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The Crip College Experience as a Model for Accessible and Affordable Community Creation

Le vécu universitaire crip comme référence pour bâtir des communautés accessibles et abordables

Joanna Tucker-Perkins
Wittenberg University
joltperkins89@gmail.com

Abstract

While higher education can be a place of self-discovery and peer bonding, it is a perilous journey for disabled individuals. Using an autoethnographic narrative as a case study in the disabled college experience, one nontraditional American student explores the ways that college communities exclude diversity. The false political rhetoric surrounding Diversity, Equity, and Inclusion has led to a rollback in accessibility, but that does not mean individuals cannot act. Through experience and practical examples, inclusion does not need to be a pricey investment, but a community choice.

Résumé

Bien que l’enseignement supérieur puisse être un espace de découverte personnelle et de création de liens entre pairs, il demeure un parcours difficile pour les personnes handicapées. À partir d’un récit autoethnographique utilisé comme étude de cas, une personne étudiante étatsunienne au parcours atypique analyse les formes d’exclusion de la diversité au sein des communautés universitaires. Le discours politique, souvent trompeur, autour de la diversité, de l’équité et de l’inclusion a entrainé un recul en matière d’accessibilité. Cela dit, les initiatives individuelles restent possibles. L’expérience vécue et les exemples concrets démontrent que l’inclusion ne nécessite pas forcément de lourds investissements : c'est l'engagement collectif qui la construit.

Keywords

Disability; Autoethnography; University; DEI; USA

Mots-clés

Handicap; autoethnographie; université; EDI; É.-U.

Introduction

College is a formative journey marked profoundly by the connections and communities forged therein. The legacies of such bonds can resonate for generations, empowering each new graduate with education and, hopefully, prosperity. The institution of higher education is rich with opportunities not only in personal exploration but also in community. Kinship has been the method of survival throughout human history, with extinction as the ultimate outcome for those denied entrance. Community becomes even more important for individuals with small or nonexistent connections to belonging, then and now. Belonging as a term may be interpreted in many ways, but for those seeking community it is a place of support, where you are valued and seen for who you are, and where you are accepted. It can also become a place to seek aid, friendship, and protection in kinship groups that have been self-created when biological kin are unable to be supportive.

In this paper I use my privileged education to mine my individual experiences as a disabled student, daughter, niece, and mother. Using lived realities as an autoethnographic case study, I will show the logistical nightmare posed for disabled students in simply navigating campus spaces. I argue that, despite conventional wisdom, it is actually more economical and pedagogical to increase accessibility for disabled groups on campus. Inclusion should be expanded across the societal lines of body type, perceived ability, identity, ethnicity, culture, or monetary worth. Education is required to make an educated decision and to advocate for your own needs. Currently, with the second term of United States President Trump, there is misinformation and a rollback of accessibility incentives in the USA. However, disability and inclusion are global issues, and only through the voices and experiences of those affected can we make practical, actionable changes.

The monetary reasons we bar disabled bodies both stifles the emergence of a diverse community and perpetuates eugenic denial of educational access. By utilizing autoethnographic methods, I seek to 1) contextualize the university system's refusal to provide resources for specifically disabled communities on campuses; and 2) paint a picture of a disabled undergraduate experience ripe with residual pain and struggle. In doing so, this paper establishes the need to shape wiser, sustainable accessibility experiences within the university system.

Moreover, I argue that we must begin prioritizing the everyday coordination of accessibility before we can affectively use resources in programs and marketing for or about diversity. After we create access, we can reassess what constitutes community for and among disabled and diverse students ourselves. Spending funds on events and classes about or for disabled students does not mean they can physically be involved. Once access becomes a serious investment, disabled students will be able to advocate for themselves—empowering us to build crip communities and a sense of belonging for students across the ability spectrums.

I am a "nontraditional adult student." That label lacks the nuances of being a generational teen mother, bred from immigrants, farmers, criminals, addicts, and genetic outliers. My personal crip pedigree is so undefined, there are currently no studies on my unique knot of mutations, including genes SCN8A, PMM2, and MTHFR. My current diagnostic list includes fibromatosis, scoliosis with lordosis, Vasovagal Syncope, C-PTSD (Complex Post Traumatic Stress Disorder), hypothyroidism, osteoarthritis, venous insufficiency, premature uterine failure, and so much more.

While these labels can be rare, what is not is my struggle for the right to exist in a community. Every day I go into a building, I know that if anything goes wrong—fire, flood, or frenzied evacuation—I will be the first to die. As a child, I was always sick and expectant of an apocalypse, where I would be first to die because I did not please Jehovah. The idea of death and life meant nothing in disability purgatory. Then, I became a mother and realized with horror the state of the world.

In 2018, I defied my family's isolationist religious expectations by going to college. I went in search of belonging. I hoped that even as a single twenty-six-year-old mother, I could find a better path for my similarly unique children. In my university's unevenly paved lots I found a community, however compromised and difficult. I found pockets of genuine care, discovered purpose in my experiences as a disabled survivor, and formed my identity and inner circle around my genuine self. Many marginalized individuals refer to this kind of cultural kinship as a "found family." Though, despite the family I found in college, I have continued to experience and recognize the ways disabled groups still do not have equal access to vital resources. Further, most disabled individuals are not in a position to survive alone or advocate for their needs. The absence of disabled voices from decisions and laws about their lives has become the standard, cyclical oppression that bars us from equal representation. There is more discourse with popular books from disabled icons like Alice Wong, but what about those of us still unheard? I seek foremost to show the need for education, how it contributes to forming a stronger community, and what we can do when policies fall behind practicality.

Prelude Prognosis

Growing up around such varied and poverty-stricken disabilities, as well as the isolation of my family's Jehovah's Witness religion, I never understood there was anything "wrong" with us. I thought it was admirably sacred to be alone and without. I was divorced with two children by the time I was twenty-two. My oldest was diagnosed as Autistic with unspecified epilepsy. My youngest was not even a year old. The realities of adulthood were a crushing force, and because of the societal norms of the community I was born into, I was alone. From a young age I was not allowed to make friends outside of my family's religion or learn about politics or other religions and cultures. I was unable to create a secondary support network and had no idea how to form one without Jehovah as a central figure. I could not even navigate the politics of disability, since I was taught the world was ending and engaging with the outside world was tantamount to death. I realized I needed to understand why my family is in a generational drainpipe, more of us fading into the dark every year. The harder I tried to "pull up" my proverbial bootstraps, the sicker I became; time was running out.

While crying at Clark County Job and Family Services, my case worker told me to go back to school. Academia was a secret, sinful dream I expected to be unattainable for a formerly parasite-ridden, malnourished child. There was no place to dream in my position. There was no magical story for an overweight, divorced, religiously outcast, welfare mom. But I craved connection, I yearned to be more than struggling. I did not want my children to be alone. I did not want them to wonder every night, as they cried themselves to sleep, what was wrong with them that they had so few who loved them as they were.

My first stop, after a painful partial hysterectomy, was Clark State Community College. The services, while underfunded, were the easiest to access. My biology professor often held her student's children while their parents took exams. When I had surgery on my feet, fellow students carried my books. I did exceptionally well academically, even as I underwent several surgeries, assaults, therapies, false diagnosis, failed kinships, and that ever-looming unknowable genetic factor that was killing us. Somehow, with great teachers and resilience, I obtained a scholarship to Wittenberg University. The experiences in this chapter of my education are where I combine science and experience to show you that we are more than just a data set. I want more than anything to be real, so that others see these issues as heavily as I and my children do.

Dr. Heewon Chang, Professor at Eastern University, studies research, and ethnography. He describes autoethnography as, "a research method that utilizes the researchers' autobiographical data to analyze and interpret their cultural assumptions" (9). Research through the study of experience is a valuable asset when a group must make decisions about and for others, particularly underrepresented or oppressed people. While it would be unethical to raise a child in isolated religious poverty just to see what they would say if they had the words and education, I am here, nonetheless. But how did I make it this far with such a genetic background?

Former Frameworks

Historically speaking, disabled persons were sent to die in medical institutions, poor houses, or suffered mercy killings in order to create a standard working society. The creation of the ideal citizen created the unideal "disabled" body as lived in the current, United States of America. Dr. Kim Nielsen, Professor of Disability studies and History at the University of Toledo, outlines the history and effects of colonialism and capitalism on disabled history in her book *The History of Disability in the United States*. In the book, Nielsen creates a line between the slave trade and colonialism to the industrial age and immigration practices. She begins by explaining how the sayings, and accompanying stigmas, towards disability came to reflect the values of colonialism and capitalism. For instance, when we say things like "that is lame" we perpetuate that disability is synonymous with "deficient" (Nielsen 8).

From the very beginning, the colonizing ships excluded bodies seen as defective or weak, meaning only passage was given to the loosely defined "able" mind and body (Nielsen 34, 42). Terminology for the different types of bodies and minds considered disabled is unsurprisingly varied, including the term "distracted." Through the 17th and 18th centuries, "Poor Laws" also considered those without means or education to be disabled (42, 60). If the family had money, a disabled member was able to be cared for in secret; but if poor, the disabled body who could not work found little help. Those injured during the American Civil War, or disfigured in industrial accidents also fell victim to

1900's "Ugly Law" that barred them from being in public (122). I find modern times to be similar, with laws passing to outlaw transgender and homeless peoples spreading across the USA.

Similarly, Dr. David Wagner writes on poverty and disability, drawing attention to the correlation between judgement of ability in "Poor Laws" and its reflection in modern Social Security disability benefits in his introduction to the American Museum of Disability. He explains that the Social Security Act of 1935 was distributed by the enforcers of "Poor Laws." These enforcers would judge if a body qualified as poor, disabled, or otherwise othered enough to lack employment. These judges, of course, came from the upper class, not from the peers of the judged. If deemed poor but abled, many were sent to "poor houses," where many who could not work stayed until they died. Similarly, in 2025, if you do not have a sponsor with money, you will end up in a bed at a nursing home or assisted living, where most of the Social Security is taken from the disabled persons.

While there remains evidence in historical texts of disability, the narratives from the disabled are mostly silent. Without an education, money, or a way to attain them, few found a way to be heard.

That is why disabled people rarely recorded the history of disability. The disabled immigrant, subject to similar judgement, even so far as to exclude those who did not appear feminine or masculine enough, were not allowed access to the USA (Neilsen 135). Even Indigenous people faced oppression in a socially disabling society. Historical excuses ranged from religious providence to the theories of natural selection and Darwinism used to inform ableist and racist ideals (Neilsen 17). In either case, disability was a sentence to isolation and early death. Lawmakers and scholars created a normative that disabled who they decided was unpleasant or abnormal. They left them without medical and educational resources, to die. The medicalized culling of undesirable genetic traits termed “velvet eugenics” by activist Rosemarie Garland-Thompson (29).

Culling is also terminology used in breeding practices among farming communities like the ones my mother and aunt were born into. When my aunt Mitzy was born, doctors told my grandmother my aunt would die young. My grandmother had lost her first baby decades earlier to what she called “water head syndrome,” now known as hydrocephaly. My grandmother simply decided this would not happen again, and she fought. When the schools denied my aunt entry, my grandmother taught her what she could. When I was born sickly, my mother took me to my grandma and aunt. From raccoons to newborn humans, my grandma became a relentless healer. Illness often kept me from school, but I learned stubbornness at the heels of disabled women. Despite homelessness, abuse, and illness, I have persisted.

As you can imagine, going to college, let alone a university, was a laughable goal for any poor farmer with disabilities. The “official” reason my aunt became barred from attending elementary school was because she could not fit in a standard desk. The community failed my family, and like others over the centuries, they sought solace in faith and religion.

Unfortunately, the concept of heaven and otherworldly justice leaves responsibility and action to an unknown, unaccountable mythic source. Misinformation, deferred mercy, and greed of religious leaders did not help the unpleasantly ill or different.

Like my aunt, many still die from neglect in nursing homes or assisted living facilities due to poor staffing in privatized, for-profit care. When I saw the dried bloody foam coming from my aunt's body, my education and experience with our disability let me know why she was dirty, stiff, and alone. The nurse seemed flustered; we had shown up before they had cleaned her. Otherwise, the underpaid medical aid was doing her best in an overcrowded, underfunded facility that the owners profited from. Unfortunately, we had no funeral arrangements because her size made the burial unattainably unaffordable. She got a plastic bag free with her government-funded cremation, which still cost us a couple hundred dollars. My dog got better cremation services for half the price and twice the sympathy cards.

My aunt's experience is not abnormal in the assisted care setting. A study done in Texas evaluated secondary reporting of abuse in assisted living and nurse assisted settings. They reported over 140,000 complaints, averaging close to one report of abuse or neglect per resident (Magruder et al. 220). It would seem that patients paid into USA Social Security just for a death sentence. My grandfather died before he could claim retirement, but he paid into Social Security for decades. His disabled daughter was discarded by the country he sacrificed his brother and health to defend in World War II. The soldiers' valor seems to have faded when it comes to fair care and funding.

Religious institutions, while giving hope and succor to able bodies, also brought into existence the horrors of Christian reformation schools and gay conversion therapy. The ableist ideals found in colonial theologies gave rise to disability education services such as “asylums,” “teachable schools for deviant minds,” and schools for the deaf or blind (Neilsen 47). In countless cases abled people sent the sick and different bodies away to die or become capital. Privatized care was, and continues to be, run for owner’s profit rather than genuine drive towards care. The threat of abuse and death forces disadvantaged groups into unfair labor, scientific experimentation, or even into abusive partnerships.

For example, when I was faced with institutionalization or marriage to an older man, I chose the man so I could finish high school. The CDC (Center for Disease Control) remarks on their website that disability affect 1 in 4 women, and 1 and 5 men. Of these, 39% of women who reported rape were disabled, and 24% of disabled men reported abuse other than rape according to a 2010 sexual violence survey (Breiding & Armour). While it may seem that an institutional stay would be preferable to abuse, a 2019 report from the Ontario Health Coalition notes that “Those who can pay get care, though it is often unregulated and extremely expensive. Those who cannot afford to pay are left to suffer” (*Report: Situation Critical* 8). Considering that the correlation between poverty and disability is firmly linked, it does not take a study to acknowledge the deadly outcomes of putting one’s body entirely into the care of a paid institution.

Yet, through the monstrously dehumanizing and isolating pain, wherever humans share experiences, a community will blossom. Children in 1800’s deaf schools created dialects even when institutions attempted to prevent the creation of standardized sign language. Some Indigenous children held embers of their culture alive in secret while at Christian reform schools (Neilsen 50). Zitkala-Sa, a Yankton Dakota woman, was sent to a Christian reform school in 1884 at the age of eight, described the erasure of cultural identity and her experiences in "Impressions of an Indian Childhood," saying, "Not a soul reasoned quietly to me, as my own mother used to do; for now, I was only one of many little animals driven by a herder" (10). Even though she was taken from all she knew, she managed to find kindship among other children, and keep shards of their heritage alive, Zitkala-Sa would continue her education until her health made it impossible, but not before writing about her experiences of creating kinship. Disabled and ostracized groups of people have shown that, in the darkest places we can form a support network. Without one, we are alone and subject to the abuses of the world.

Without communities that can communicate in an educated way, we will continue to misunderstand or even deny basic needs necessarily to any that survive long enough to retire.

The current institutional practices, set to serve a dominant social class devoid of diversity, will continue to fail us if we continue to leave the subject of disability separate from the voices of disabled people. In recent decades there have been more attention to disabled voices, but barriers remain. How could those barriers be understood if we are not there to express them?

The movement #OwnVoices that developed on social media platforms in 2015 focused on uplifting marginalized voices in writing. The term was dropped by organizations such as Book Riot and We Need Diverse Voices, due to the gate-keeping aspects of identity labels and the dangers of "outing" one's diversity for public scrutiny (Lapointe).

While the extensive history of colonialism, industrialization, and the creation of the ideal working citizen has caused the problems of generational poverty, desperation, and death, this is the only world we have. My goal is to show a small step towards a transition to inclusivity that will not only benefit disabled people but create a more sustainable and profitable work force. The very first step, before we create a community, and before we educate or direct, we must make areas accessible. To do that, we need to work in our communities, but how do we do that with so many barriers?

Present Politics

The Americans with Disabilities Act of 1990 created a federal standard to allow equal access to educational institutions. Though that is the federal law, I have never been in a building I did not struggle to physically enter. Automatic doors, elevators, and low sinks may be mandated by law but there is no pressure to create compliance. Sometimes industrialized countries fund enforcing agencies, but I have not been to every building to establish if they themselves follow their guidelines.

Similarly, I have trouble getting my wheelchair into judicial buildings, Social Security offices, and even my doctor's office. All the avenues I have been directed to use to advocate my needs are inaccessible because of my needs. The "success" center at my college was located uphill, with "handicap" parking behind the building and no accessible entrance from said parking lot. I visited the office there and the library in general three times, finding ways to avoid it and access online sources rather than slip on ice or lock my arms up trying to get into the building. Even obtaining the reference list for this paper, I had to pay out of pocket because not all my sources were free or online accessible. These barriers effect how and where I can advocate for myself, and what I can learn.

Similarly, I cannot get assistive gear or medical treatment to improve my education or research needs without money, which I cannot get without a job, which I cannot get without an education, which I have struggled to get with only a second-hand medical transport wheelchair. Eventually, in desperation, many disabled people take menial jobs at poverty pay until we either die or Social Security approves us for a meager and unstable distribution of the funds paid to them from our paycheck when I or my family were able to work. I hope that is just in the USA, but I do not see as many differences between us and other industrialized nations as I would like. I have lost disabled kin on every continent, needlessly.

I have watched disability and need my entire life. I still did not fully understand disability’s draining, unnecessarily painful, and redundant hurdles until I was a disabled adult, reliant on mobility aids. More than once, I emailed a professor from the parking lot, crying, because there was no way for me to get inside to class. It was then that community saved my son’s life and ensured my education. While counselors told me to transfer out, that I could not handle university life, the English department came to my aid. I was fortunate that these kind professors and students saw my need and chose to help me. My mentors encouraged me and connected me with resources. My student peers helped me take notes and attend remotely when the professor had trouble connecting to me. One professor obtained lifesaving medical equipment for my son when he couldn’t breathe, and another helped transport me to an MRI that prevented unnecessary surgery. Over and over again, I found a supportive emotional connection behind every door in Hollenbeck Hall. Whenever I wanted to give up, there was someone asking me what I needed to keep going. I have the words now, but before I did, I needed those advocates.

I was fortunate that the COVID 19 pandemic created accessible classrooms, with equipment to enable distance learning. But even before the mass mask mandates were lifted, it was policy to leave my accessibility needs up to each professor’s discretion. I had to rely on the professor’s individual drive to use distance learning equipment that had already been installed into each classroom.

Furthermore, during my first year at Wittenberg University, my mandated “success” coach said they could give me accommodations for test taking, but if I could not make it to class because of my disability or that of my dependents, I was unprotected. I did not understand how the school would accept me, knowing who I was, just to let me fail. My professors and fellow students, after hearing my story, gathered at my side. I managed to graduate in May of 2024, my niece pushing my wheelchair in the mud straight to the car. I missed the chance at photos and handshakes because I could not afford an innovative wheelchair, like the graduating speaker from Apple used. They gave this disabled woman an honorary degree, pretty as a picture, while I gazed at my hard-earned diploma splattered in dirt. I did not have much anger at the situation; I was amazed I was there at all. There were buzzards above me, and I was filthy, but I made it farther than the last generation. My children can go even further.

I am not the only one to suffer themselves into success. Dr. Marisa DePicker outlines in a paper that while many institutions were happy to talk about accommodation, they were underutilized and were unfamiliar with assistive technology, creating a barrier (De Picker 164). Meaning, the will to help is there, but the education isn't a guarantee. Teachers and students can remedy this by taking the incentive to learn the technology their university provides, and how it can aid in distance learning. While some institutions have embraced streaming and digital avenues of sharing information, the accessibility options are not a guarantee, making education a pricey risk for poverty stricken disabled families. Why not maximize the use of the COVID-19 resources, especially when businesses are becoming increasingly online or performed at a distance? Isn't college supposed to teach us about the world? Why then are we not teaching students how to interact with all its variations?

As time moves forward, more varied groups have gained access to equal employment. The United States Department of Labor reported the unemployment rate for people with a disability was 7.2% while the rate for those without a disability was 3.5% ("Persons with a Disability: Labor Force Characteristics Summary"). We do not want to die in facilities; we want to work and live like everyone else. I want to take my children to the movies on weekends and vacations once a year. I have never had the money for those things, for more than survival and rebellious little joys. My joy does not need to come at the cost of society, because with common courtesy and practical changes I can work my share, gladly. The need and desire for work also means the need for education.

The growing demographic of "nontraditional" students, if necessary, are a consumer base. The more these people make, the more they spend, the more they work, and so forth exponentially. There is an increase in nontraditional and disabled students. The percentage of schools with 10% or more students with reported disabilities has gone from 2.4% in 2010 to 11.8% in 2021(“Digest of Education Statistics, 2022”). According to the National Center for Education Statistics (NCES), the overall reported enrollment of identified disabilities was 21% of undergraduates, and 11% postbaccalaureate. The population examined in the data set is distributed primarily between public and non-profit education sources according to NCES.

Why the influx? Several factors affect the success of disabled students. The increase in survivability of once deadly illnesses paves the way for more mutations, and increases the need for workers to feed, cloth, and educate families with disabilities (Barnes 442). The need for income to pay for medical care and basic needs is universal; we all need care at some point.

While survival explains why we exist in university spaces, it does not show you the struggle we face for the same opportunities as those who have standardized bodies and minds.

The single biggest factor to the success and acceptance of disabled students was the commitment of universities to support the students (Safer et al. 7). Studies show a better retention and grade point average in students who receive support, yet many disabled students do not use onsite support services. The roadblocks to many of these students, when asked, were knowledge and access to the support services, as well as the stigma of receiving such services (Groah et al. 110; Jorgensen et al. 22). Personally, I could not get up the ramps that were there specifically for me. As science would have it, wintry weather and precipitation makes all the winding, uphill, “accessible” areas icy. While the last Ice Age ended 40,000 years ago, we have yet to defeat the simplest adversary to advancement; weather.

As support for a disabled body can vary person to person, we must have one basic aspect to create community, to create support, and advocate for our individual needs. That is, accessibility to education, and that begins with communication between disabled students and the ones making decisions.

Practicing Practicality

While legal agencies and laws are lovely ideas, without understanding and implementation, these measures are hollow, wasted progress. Integrated schooling does not always require a new curriculum, or more accommodation than what federal law requires already. The tools and resources obtained during distance learning in the COVID-19 pandemic should be utilized by and for the demographics that need them. With the technological age in full swing, we do not have to isolate ourselves anymore. The basics for integration, understanding, and access that exist now show remarkable results. Students and instructors also expressed positive reactions to learning with disabled peers (Travers et al. 45). Educational diversity and access are important for expanding the community and teaching younger generations how to interact and care for those who are different. Empathy, patience, and observation can and should be taught and experienced. Integration methods are not a new concept, and studies exist showing benefits of educating varied groups together. So why aren’t we using them?

When discussing inclusion in disability education there are three popular approaches: theological, medical, and social. Theological approaches include religious bias and as discussed, may care for their version of acceptable disability, but not in a way that encourages educational or social growth. The medical model of disability was introduced by the World Health Organization (WHO) in 1976 and published in 1980 (*International Classification of Impairments, Disabilities, and Handicaps)*. While the intention was to identify disabilities, treatments, and communities in need, it has become a barrier for the disabled. Medical models place the burden on disabled individuals. First, there needs to be a way for them to attain a medical diagnosis, then getting that info to the needed places to get assistance. That assumes the individual understands how to navigate their local systems for assistance, and the starting money to get medical treatment. These steps can be insurmountable obstacles in areas without busing, online access, or specialists for a person's particular disability. There are so many factors and steps, I could write another paper on these alone. My family has been trying to navigate them for generations. All the medical diagnosis in the world do not help if, like me, the disorder is not understood enough to be neatly put in a diagnostic label.

In the USA, Section 504 of the Rehabilitation Act of 1973 guarantees accommodations for disabled students in the classrooms of public institutions. Disabled students are required to collect documents from their doctor with specific requests based on their diagnosis. One example of common accommodation is extended test times for someone with anxiety. The paperwork must be extremely specific and state the diagnosis, and recommended length of extension, or the paperwork process starts anew. The paperwork bureaucracy is one of the many hurdles faced by disabled people in every single institution. The greater the deviation from "standard," the more proof and time and testing is enforced upon the individual to exist in society.

The social model of disability is a framework for disability studies, coined by the disabled Dr. Mike Oliver. In the updated 2012 edition of *The New Politics of Disablement,* Oliver explains that "the social model breaks the causal link between impairment and disability. The reality of impairment isn't left behind, but is not the cause of disabled people's economic and social disadvantage" (Oliver 21). Oliver continues by stating that the disabled body should not be considered the flexible aspect, but the environment.

While the individual examination of needs is a social model based on the varied experience of existing, it still places the burden on disabled individuals to justify their needs, again placing the bureaucracy on the disabled (Mole 63). The expense of doctors, mobility aids, travel, and even printing paperwork fall onto disabled students. In addition, the accommodation is not always honored or protected, such as with attendance policies for medically necessary absences. This extends to caretakers, like me, who would miss class due to the care of a disabled individual. Going to college becomes an expensive gamble, with barriers both visible and invisible.

The idea of taking away the social barriers by creating an accessible atmosphere to begin with is what influenced the concept of Universal Design & Universal Design of Learning (UDL). Both designs intend to make classrooms and public areas universally accessible. Arguments about UDL seem obvious; no one experiences disability universally. Dr. Aimie Hamraie, a disabled professor and design researcher, examines the intersectionality and prospects of UD in their book *Building Access: Universal Design and the Politics of Disability*. Hamraie emphasizes that UD has not taken into consideration the nuances of disability, and the intersectional experiences of the individual. Instead, the selling point seems to be "universal design for universal good."

Dr. Jay Dolmage of the University of Waterloo elaborates on the detracting thought of a universal design as a concrete basic method of building. UDL, Dolmage argues, should be a starting point, not a set of bullet points for universities to tick off. Rather, UD should be as the universe, evolving. What was a practical idea of design in the early 2000s is now a contested outline that is antithesis to its title. The only universal experience is that there is no entirely universal experience; we can all have commonalities but none of us have the exact same genetics, class, gender, race, or lives. I propose we reexamine what UDL means and stop trying to make a binary out of the genetic jazz of existence.

I will refer to the evolving idea of UD as Universal Design of Learning Reimagined (UDL-R). In my imagined theory, students ask for accommodation in the classroom itself and do not have to seek bureaucratic interventions. Practical changes to education for the purpose of this argument are minor adjustments or cost-efficient uses of space. A few simple examples would be classroom webcams, removable chairs, adjustable tables, entry way transition rugs, and more family restrooms for use by any gender or ability, complete with emergency alert. On larger campuses, golf carts instead of buses help get not just disabled students to and from classes, but injured athletes. You could even make deliveries. Multiuse does not mean Universal, but again, the idea of Universal should mean changeable, not static one-size-fits-all.

Webcams are a standard addition to laptops and continue to be a part of distance and home-based learning since the COVID-19 pandemic. Distance learning was the only way I could attend classes during my surgery recovery, and when I lost the ability to drive safely due to vasovagal syncope. The more commonly available items such as basic metal folding chairs rather than the combined desk chair model easier to attain and offer an immediately adaptable learning environment. I would not have had to arrive to classes early and spend energy rearranging furniture if it was simple aluminum folding chairs and the professor could make space themselves. UDL-R should create an environment where professors can bypass certification processes and needless bureaucracy, making less work for all parties. If we can move a chair ourselves, rather than file paperwork to have a bolted down desk moved, we save time and money for everyone.

Adding strips of outdoor traction tape to inclines would have prevented my wheelchair from slipping, and my resulting injury. Adjustable lights and noise filtering headphones can aid in stimulation concerns and would have prevented quite a few migraines and meltdowns for myself. At the end of my education experience, alternatives to essays, including extensive visual storytelling and musical composition can aid in conveying a student’s retention of class topics while allowing those with varied expressive abilities to maintain grades. Having all serious test taking scheduled in smaller, distraction free zones would cut down on the need for extended test times and location.

The possibilities of making an environment that evolves with need is within our grasp and can grow as we discuss it with students and our communities.

A negative aspect to creating a malleable environment is the possible need for more training for professors, straining an already overburdened faculty. The solution is the same as for us; make the learning easier, simpler, and cost effective. If the physical facility is adjusted in small ways, the professor will not need to exercise all of the necessary adjustments. During the COVID-19 Pandemic, it was reported that schools took extraordinary action to ensure technology and internet access for students (NCES). If given the tools, teachers can aid their students. If knowledge of technology is the barrier for them, then an online course on the subject is the answer too. However, if online is unavailable, a list and guide of some options and the available technologies would be better than the last-minute frantic flight of the pandemic days.

I guarantee though, we are happy to advocate if you give us a chance to do it without breaking us before we get through the doors. Whether by note, vocal device, service animal, email, or image, we will try to convey our needs. We just need institutions to listen and keep trying. I wouldn't even be alive if there wasn't a long line of stubborn mothers, and tenacious teachers who helped me succeed.

Further, COVID-19 has shown we can adjust for those who can't be in person, so why make it mandatory? If professors can easily teach online, and the grade outcome shows that the student body is learning, why force disabled students into classrooms and campuses that are not designed with them in mind? While attempting to outmaneuver ADA compliance, we have only created a market full of extra costs. A door jamb is less than twenty dollars, but the lack of one could mean the difference between access and oppression.

As we have already seen, there is an increase in nontraditional and disabled students, and that is without large scale implementation of accessible, universal designs. Accessibility can save money on materials while increasing the student body and thus income for universities. Money is a harsh truth that we may seek to dispel but first need to navigate. It is no longer economical to bar "abnormal" bodies from public places.

In a glimmer of hope, universities and colleges in the USA have begun adopting Diversity, Equity, and Inclusion (DEI) centric policies following the Civil Rights Act of 1964. The aim was to encourage diverse groups of identities, histories, and experiences to join schools and work forces. This includes low-income, disabled, Black, and immigrant bodies, among others. While DEI acts as a framework, it is only that and relies on adoption and interpretation by each institution. Despite the possibilities to expand student base, community, and even economic spending, the adage has become "go woke, go broke."

In fact, current political climes have impacted social views of DEI spending. As I drafted this article, United States President Donald Trump rolled back Diversity, Equity, and Inclusion. The "government watchdog" organization OpenTheBooks, also known as American Transparency, is OpenTheBooks is another name for American Transparency, a nonprofit 501(c)(3) business, meaning they only pay the taxes of a "charitable, religious, or educational" business. However, with only seven employees, they made a profit of over 3.4 million in 2023 (Quinn).

OpenTheBooks has been the reporter of extreme spending for Diversity, Equity, and Inclusion. Recently, Fox News host Jesse Watters cited OpenTheBooks numbers, saying, “If you haven’t realized by now that DEI is a grift, let me just take you to school—specifically the University of Virginia, which spends nearly $20 million a year on DEI” (Watters). The implication is that the government is supporting DEI at the expense of taxpayers and taking fair opportunity away from “average” students with comparable abilities.

However, Adam Andrzejewski, founder, and chief executive of OpenTheBooks, expects transparency from institutions but does not disclose his own financial backers. When questioned, he mentions Republican funding or refuses to acknowledge questions on who supports his “research.” The sensational $20 million annual spending OpenTheBooks claims the University of Virginia spent on DEI includes almost half a million for Dr. Tracy M. Downs, UVA Health’s chief diversity and community engagement officer. Dr. Downs is also, according to the university, a professor of urology, specializing in the surgical treatment of urologic cancers. Dr. Downs sees patients through the college’s facilities (Quinn). Following the trend of misrepresentation, other jobs listed as DEI spending are related to federal laws such as Title IX and ADA compliance. The compliance officers employed are generally able-bodied, as were the politicians who wrote, approved, and enforced the abled idea of accessibility.

Yet, DEI is a practice adopted by universities, so the idea that there is DEI spending leaves us to ask, what are the parameters for a universal measurement of DEI, to record staffing and spending? The answer is that there are none, and the numbers vary across studies done by primarily politically conservative organizations. The boogeyman of Civil Rights and Equality bankrupting institutions, it appears, is nothing but skewed numbers and biased political agendas.

Perhaps most telling of all is the silence of disabled students in these conversations (Mole 68). We are not included because we do not exist in these spaces at all, or we are so overwhelmed by advocating for the simple ease of getting through a door that we do not have the strength to explain why we should all be able to use doors. In a collection of papers from disabled professionals, one scientist comments:

> . . . Students with disabilities do not always agree on the best practices for UDI. Overall, however, they make it clear that universal design strategies represent good teaching practice and minimize the need for specific accommodations. (Durre et al., 2008:85, 95)

In this extensive line of shifting responsibility, disabled people are dying in poverty because of needless exclusionary practices. If we cannot afford a wheelchair, how does anyone think we have the money for a lawyer to sue for our rights? If there is an issue with a building's ADA compliance, we have to first find a lawyer to take our case, then pay for filing, court, and any other costs to pursue equal access. As discussed by Neilsen, poverty and disability come hand in hand. It is not feasible to expect every disabled person to pay for what was already legally upheld but not enforced. Instead, like with health care, education facilities love to keep us in circles until time takes care of our desperate voices.

A further barrier, once education is obtained, is the ability to find a job. In the United States the term “work at will” means that employers can fire without citing a reason. The current political regime does not support hiring for the sake of diversity, meaning that there is no pressure for employers to make a workplace accessible. London disability research specialist Dr. Jason Olsen used lived experiences of disabled workers to understand why there were barriers to reasonable accommodation (RA) in the workplace. Though under UK law employers should make RAs, some workers are not disclosing their disability. To understand the hesitancy to disclose disability needs, Olsen evaluated the responses of employees who have pursued accommodation. What the study found was that the process of accommodation “requires them (disabled peoples) to face a gauntlet of barriers, each of which can terminate their efforts to be gainfully employed or to advance” (Olson). Further, those interviewed expressed that the cause of the barriers they face came from “weak legislation, uninformed or unwilling employers, ill-equipped managers, unknowledgeable human resource (HR) professionals, and the prevalence of prejudice and stigma against disabled people’s value as employees” (806).

Unable to learn, unable to work, and unable to sue for advocation, what are options for the disabled if there is not a community to support and empower them? I only hope that, in some tangible way, we make the changes ourselves when the government wont sanction the inclusion efforts. All I ask is to question why a classroom lacks diversity, and if there is an actionable solution. Then, by each adjusted chair and frugal purchase, we can make classrooms as varied as our existences.

Conclusion: The Persistent, Perilous Future

I told my son yesterday that he cannot safely go to college because DEI cuts have cost many of my kin group at Wittenberg to lose work, and I could not guarantee his equal treatment at any other college. I felt that failure, betrayal, and pain as a person and parent all over again. However, unlike when this all started, I am not alone. There are more avenues to connect and create a community now and we can fight together for access. I will keep learning and advocating for an end to this needless struggle. I have known poverty my entire life. I have seen my father die and my children suffer because of their genetics. I have cried in public buildings I would later never be able to enter again without the aid of a partner. Yet, it was not until I saw the deceased body of my aunt, cold and alone, that I realized education did little without the community. A community I made in college.

My beloved aunt was dead before she turned sixty, and my family said she was a miracle. Like my son, she was supposed to be dead before she was sixteen. What miraculous horror, that survival was the only concern, and thus they were triumphant with every meagerly bought hour gifted by the able bodies among them. I did not understand the cruelty, or why “Mental Retardation, Developmentally Delayed” was a valid cause of death on Mitzy’s death certificate. I still do not understand.

My isolation, though less extreme than my aunt’s, had kept me from the vital knowledge of community action and cooperation. If I’d had support, I could have found answers in college and found sustainable work before years of labor destroyed what health I had in my youth. My children, whose lives I bought with my health, survived only from that community. My professors allowed me the space and resources to prioritize my children, my health, and obtain medical equipment that saved our lives. I went to college too late, as my health has drained faster than the precious years of my children's lives. If it had just been sooner, I know my mind and determination would have done amazing things. I would not have to fight the pain of tumors, damaged bones, and intrusive violent memories if I'd had I found in college. If I'd known I could feel a sense of belonging, of acceptance, I know I could have changed the world. I know my children can if we let them.

Whether disabled children are seen as our future or just another consumer, we need them. If given the chance, we will show the world that disability is not synonymous with death, but it all must starts with an open door.

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