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IHED'S MISSION STATEMENT:

The International Higher Education and Disability organisation, IHED, unites the disabled community and allies at Harvard. Based at the Harvard Graduate School of Education, our core mission is to provide a forum for the discussion of disability and disability-related topics. IHED is at the forefront of expanding disability awareness across Harvard's campus, exemplifying the importance of contributions by people with disabilities to the critical discussion of diversity and inclusion in higher education.

ACKNOWLEDGEMENTS:

We first acknowledge some of the many individuals who helped us produce this publication. Everyone who agreed to be featured in this publication has earned our deep appreciation and respect. We would also like to extend our deepest gratitude to Dr. Thomas Hehir, who brought the members of this project together and taught us so much about disability narratives.

We also thank all of those who supported us in the production of this publication. Our editorial team at IHED have been truly fantastic in providing endless support. Lindsay Burris, Shannon Daniels, Sarah Sanders and Mary Beth Spang deserve further recognition for their efforts to work directly with the writers. We would also like to express our appreciation to Inés Benítez Gómez for designing this publication.

Finally, we would like to thank the Diversity and Innovation Fund and the Office of Student Affairs at the Harvard Graduate School of Education, without whom this publication would not be possible. A special mention goes to Tracie Jones, the Assistant Director for Student Diversity and Inclusion Programs, and Maritza Hernandez, Associate Dean for Enrollment and Student Services, for all of their encouragement.

Co-Chairs' Letter:

04/2019

Our journeys of identifying ourselves as disabled – blind and dyslexic, to be more specific – have been quite different. However, when we met in the course taught by Dr. Tom Hehir, titled "Implementing Inclusive Education" at the Harvard Graduate School of Education (HGSE), we felt drawn to one another. We both felt that it was important to include disability in the conversation of diversity and inclusion at HGSE; we both believed that our disabilities were an asset; we both wanted to bring students with disabilities and allies at HGSE together. That is how the student organization, International Higher Education and Disability, came to be revived.

Amplifying the voices of students with disabilities and allies through a collection of writings was an idea initially conceived by Nikita, but welcomed by everyone who was present at the first meeting of IHED in October of 2018. Six months since that initial meeting, we are excited to share this publication with the HGSE community and beyond.

Although contributors to this publication are united by our lived experiences and connection with disability, each and every person in any disability community experiences disability differently. For some, they have no choice but to disclose their disability in every instance; for others, their disability is invisible until they explicitly disclose it. For some, it is a chronic health condition that manifests itself physically; for others, disability takes the shape of mental illness. For some of our writers, disability - whether visible or invisible - is a constant fact of their personal lives; for others, family members, friends, or students they deeply care about are disabled in one way or another.

The different ways in which the contributors are affiliated with Harvard also show a dimension of diversity in this publication. Although the majority of the contributors are current and former master's students at the Harvard Graduate School of Education, students from the Harvard Kennedy School, Harvard Law School, Harvard Medical School, and the Harvard Graduate School of Design are represented in this publication.

Finally, the topics and styles of the pieces in this publication are broad in scope. They include personal narratives, academic essays, proposals, and everything in between. We intentionally left the submission guidelines open so that the diversity of disability experiences and academic backgrounds could be expressed freely and authentically.

Although the discourse on diversity and inclusion is increasing, we often notice that conversations surrounding disability are cast aside or neglected. We hope that this publication will be a platform through which more students, faculty, and staff at Harvard will begin to openly discuss disability. Moreover, we invite you all to the journey of finding your place in the disability community because disability, in one way or another, is an inevitable part of the human experience and an invaluable element of human diversity. We believe every person has a place in this community.

Nikita Andersson and Miso Kwak

Foreword

Dr. Thomas Hehir

When I was a student at Harvard in the late ‘80s there were very few students with obvious disabilities. I remember one man who was blind and that was about all. I never saw sign language being used nor did I see wheelchair users, as most buildings were inaccessible. Though I had devoted my career to expanding educational opportunities for students with disabilities, I did not meet a single student with an “invisible” disability, such as dyslexia, who was “out” about their disability.

When I returned as a faculty member in 2000 things had changed. Teaching courses on disability I met many students who had obvious visible disabilities such as cerebral palsy, deafness, and blindness. Further, I started meeting students who were “out” about being dyslexic or having ADHD. For me this was an important and welcome change. I ultimately wrote a book about some these students, How Did You Get Here: Students with disabilities and Their Journeys to Harvard, which sought to tell their stories. My primary motivation in writing this book was to counter a prevailing narrative, too prevalent in elementary and secondary schools, that disability and intellectual accomplishment were mutually exclusive. This ableist assumption is evident in lack of enrollment in AP classes and gifted programs, many of which never enroll students with disabilities. Unfortunately, low academic expectations for students with disabilities are pervasive and pernicious.

The stories these students related were varied but a consistent theme was their desire to confront ableist assumptions about their capabilities and their drive to pursue their intellectual interests. At times educators supported these students, and at other times they did not. Unfortunately, not all of these students found a welcoming environment at Harvard. Some had to continue their fight to get appropriate accommodations. Others found disability services that they had not encountered in previous environments that enabled them to thrive.

This is why this publication is so important. The voices of these students and their allies are part of a wider movement on the part of the university to promote diversity and inclusion. Yet the voice of disability is often neglected in these efforts. These students are changing this. The testimonials and essays included in this volume provide important institutional memory upon which future progress can be built. As new students arrive at the university these voices can help connect them to the past as well as provide future directions in confronting ableism and promoting inclusion.

The struggle for diversity in inclusion goes on, and these students have done their part to build a future in which students with disabilities are not just welcomed but receive the equal access to all the university has to offer.

Contents:

Untitled

Mary Beth Spang

Mary Beth is an Ed.M. candidate in Human Development and Psychology at HGSE and will be graduating in May 2019. The sections of this creative non-fiction essay depict some of her experiences managing Panic Disorder, Generalized Anxiety Disorder, and Major Depressive Disorder in her life thus far. The sections originated as journal entries written post-panic attack(s). Mary Beth was inspired to compile the journal entries for this piece as an exercise in processing and accepting her illnesses upon hearing one of her professors, Nancy Sommers, say “We all write our way to understanding.” She furthermore hopes that sharing this writing facilitates awareness of those living with mental illness as members of the disability community.

***

1:25pm. She is typing an e-mail to a colleague when suddenly, panic appears. It stands there in the threshold between the hallway and her office, and she freezes. She worries that someone else will notice panic's presence, so she invites it inside. This is her first mistake.

She's not sure if panic plans to stay. She thinks, maybe if I start working again, it will leave. She tentatively begins to type, but it interrupts, asking how she is. She ponders the safest response, fingers hovering above the keyboard. I'm okay. Working.

Panic says she seemed upset last night. It knows she didn't sleep well. She adjusts her hands, clasps them together, and rests them in her lap. She stares at the ground. Then she glances up and flashes panic a smile. I'm better now. Thanks for your concern.

Her hands return to the keyboard and her eyes to the computer screen. Wide-eyed, panic peers through her because it knows that she is lying. She exhales. Go away. I'm tired. Second mistake.

Panic doesn't leave. She takes a few deep breaths.

I am not smart. I am lazy. I am childish. Lost in insults and fretting over the truth of these statements, her thoughts spiral. At what point do these criticisms earn the title: facts?

Panic continues to stare at her, silently. She inhales another awkward and uncertain deep breath. She notices fear churning throughout her body—in her stomach, chest, jaw, and fists. Scared and confused, she proceeds.

I am bad at my job. I am lonely, and my friends avoid me. I will never be good enough for anything, anyone -- my father, mother, partner... I cannot do this; please get me out of here... Help me... She is crying now, sad and defensive. Four, five... maybe six uncomfortable breaths occur, these ones at a more rapid pace than before.

Panic shifts toward her, opens her arms, and positions itself inside her embrace. She is defenseless against its penetration. Its breath begins to mirror hers. Their chests rise and fall, hearts beat, and hands quiver in sync. She decides it's best to stay quiet in this moment for fear that panic will escalate and burst into rage.

She worries that someone might overhear them. Together, she and panic stand up from her chair, reach, and close her office door.

Panic faces her, their bodies still linked. Its eyes, increasingly narrowed, glare through her. She tries to hold her breath. Her heart is beating so loudly and quickly that she has no choice but to exhale. I'm sorry. What can I do?

It stares at her, expectantly.

I'm sorry. Just give me a second. Let me think.

You think too much. Her tears remain silent, but her heartbeat continues pounding.

I'm sorry, she pleads, please don't hurt me.

They stand up from her chair and panic lunges. It knocks her chest forward and backward, rocking, abruptly and then steadily. They feel dizzy. It is inside me. She identifies a wall behind her. She leans back, wishing the wall could hide her from this monster -- Please, disguise me, confuse it, convince it to get out of me. She fights back, and its response suggests endurance.

Oh god, am I screaming? Panic, don't hurt me. No, not today.

Its fists connect with her gut, beating the air out of her lungs. Tears falling and gasping for breath, she forgets. Am I making any sounds? Many and varied.

In unison, their mind screams, I am worthless! I am so stupid! Why am I doing this?

She feels another shot of pressure connect with her chest. I think I am falling. Dizzy, she sees blue and grey absorbing each other. Panic shakes her, uncontrollably. She is numb. How long will it last?

She hears a crash, and everything stops.

Hours, minutes, or seconds later, she regains consciousness. She looks around the room. Is it really gone? She touches her cheek and realizes that it's soaked. Her eyes continue to well, and tears fall, gentler than before. It's over. Relief, as well as sadness, ensue.

She stands up. Her hands reach for the chair, and her eyes search for the computer screen once more. 1:37pm.

***

"Instructions to the Health Care Provider: The employee listed above has requested leave under the Family & Medical Leave Act (FMLA) to care for your patient. Answer, fully and completely, all applicable parts below."

***

She feels sick. Her heart pounds and body shivers. Is she sweating? Thoughts jump to the worst possible scenarios and conclusions as panic enters.

Trapped inside with emotion that might spill out at any moment, her brain cries for help.

What can she do? I can't embarrass myself at work. No one can see me like this.

Across the hall, they discuss numbers. Inside her office, door closed, she fidgets, worries, hopes no one notices, and prays that panic retreats.

The air doesn't feel like enough. It's not getting to her body fast enough. Enough, enough, ENOUGH, her mind screams.

Stop escalating. Take deep breaths. Focus on the sound of each finger pressing a key. Transfer your energy into words. Compartmentalize the pain.

Breathe in—count to five—Breathe out—count to five. Repeat.

***

"Was medication, other than over-the-counter medication, prescribed?:

_____No___x__Yes."

***

One second, she's swallowing a spoonful of warm tomato soup. The next, panic strikes.

Gasping for air, she hyperventilates. She sways back and forth; no part of her is still. Her dog sits up, looking alert, and tilts his head. She is aware of this but unable to answer his questions.

Her dog remains in front of her, barking for her attention -- his wide, curious eyes fixed to hers. Panic shouts, attempting to disorient and dissociate her. Her dog continues barking, and his eyes refuse to abandon her, grounding her from panic's attempts.

Her dog leaps into her lap and frantically nuzzles her face, arms, and chest. He kisses the salt from her cheeks, replacing the moisture of her tears with his sloppy saliva. She wonders how her dog knows what to do.

She stands up to get a glass of water. Her dog follows. Fumbling through her purse for medicine, she finds the bottle of Ativan, removes its cap, and drops one pill in her hand. She rests the pill on the back of her tongue. She sips water and swallows.

Anxiety lingers, but panic withdraws.

***

"Will the patient need to have treatment visits at least twice per year due to the condition?:

_____No___x__Yes."

***

She attends therapy twice per week, visiting her psychiatrist every other.

Shame thrusts her a blanket; when she's not at therapy, she crawls underneath. She wants to feel loved and comforted by human embrace, but this camouflage is enough.

Her pain has no beginning or end; it flows throughout her like the disease that it is, rooting in crevices she can't identify within her body.

***

`“Will the patient be incapacitated for a single continuous period of time, including any time for treatment and recovery?:`

`_____No___x___Yes.”`

***

“Can you look at me?” her friend asks.

She doesn't answer verbally, instead lifting her eyes, consumed by fear. She has previously described the experience with the words: It feels like I'm dying.

Besides her friend, panic occupies the room.

“That's it, focus on my eyes,” her friend continues.

As time progresses, her friend remains, steady and gentle. Tears flood and consciousness vacillates until panic departs.

***

`“Describe other relevant medical facts, if any, related to the condition for which the patient needs care (such medical facts may include symptoms, diagnosis, or any regimen of continuing treatment such as the use of specialized equipment):`

`(1) Major Depressive Disorder, (2) Generalized Anxiety Disorder, (3) Panic Disorder”`

***

She curls into the chair, clutching a pillow, feeling unbalanced by panic's presence. Breathe, she begs.

What did her therapist teach her?

Deep breath in through the nose -- count to five -- deep breath out through the mouth -- count to five. Repeat.

Deep breath in through the nose -- I hate myself -- deep breath out through the mouth -- I hate myself. Repeat.
I hate myself. Repeat.

I hate myself.
I hate myself.
I HATE MYSELF.

I HATE MYSELF.

I HATE MYSELF.

Repeat.

She can't catch her breath. Her dog barks. Confusion and terror bombard all senses. She gasps. She clutches. She fights. She flights.

***

`“Estimate the beginning and ending dates for the period of incapacity:`

`_______Unknown_______”`

Black Disabled Students in America's Schools

Harmonie Coleman

Harmonie is a master's candidate in HGSE's Teacher Education Program and will graduate in May of this year. As part of her program, she currently student teaches 7th grade ELA at Boston Latin Academy. Before coming to HGSE, Harmonie attended Emory University in Atlanta, GA and worked part-time counselling and tutoring students with disabilities. Through those experiences, she saw upsetting disparities in how disabled children of color were treated when compared with their white peers, and became invested in changing educational outcomes for these students. After graduation, Harmonie is looking forward to focusing more on this work as a special education teacher in New York City. This work is dedicated to her students: past, present, and future.

I began teaching at Emory Autism Center's Walden preschool. To encourage inclusivity, the school welcomed both typically-developing and autistic children. I taught in the toddler classroom, where I changed hundreds of diapers, sang oodles of nursery rhymes, and played a number of invisible guitars. Our primary goal for the autistic children was the acquisition of language.

Michael, an autistic child, was two years old when he arrived at Walden. His main modes of communication were pointing and babbling; his parents had never heard him utter a word. Michael loved cheese bites, the playground, and most of all, the piano. I remember this because, to prevent him from crying, I often had to carry the little blue instrument with me throughout the day. By association, I became Michael's favorite teacher. I conducted all his one to ones, or fifteen-minute, purposeful lessons. I'd stand up and hold my hands out, and try to get Michael to say "up." I did this two times a day, three times a week, for four months. The fourth month, before I could even reach out my hands, Michael exclaimed "up" three times in a row. Smiling as he shouted the word to me, he jumped as high as his little legs would take him, and I scooped him up mid leap. In that moment, I knew that I wanted to be the kind of person who helped little boys and girls find the power to speak.

Later that year, life introduced me to 12-year-old Cleveland resident Tamir Rice. I met him the same day he stopped breathing. I saw his face—prepubescent and gleaming—on every media outlet's late-night news and on everyone's social media pages. His smile, cherub-like and not-quite-yet masculine, etched itself into my memory. Tamir received special education services. The day of his death, I imagine him playing at the park without a care in the world. I imagine him pretending to be a soldier, running around defending his fellow companions from the enemy. I imagine him pointing his toy-gun every which way, oblivious to how dangerous he may be perceived. I imagine him being confused at the sudden arrival of the police officers. Not alarmed. Just confused. I imagine him trying to explain that he was just doing his job... right before the first bullet hit his chest. I think about how these officers were so terrified of twelve-year-old Tamir that they shot first, and never asked any questions. I imagine their faces when they found out the gun was fake. And I am furious. In 2015, a jury found the officers not guilty. I am still furious.

With Michael, I saw what could happen when disabled children had access to equitable care and treatment. His growth excited me, and I remember my time at the autism center fondly. With Tamir, I saw what could happen when disabled kids were criminalized. I was eighteen when he was murdered. My exposure to "the real-world" was minimal, but I was paying enough attention to notice an important detail. The children I taught at Emory's Autism Center, the children whom I so loved and protected, were predominantly white. Tamir, age twelve, was Black.

I have witnessed how we favor those whose bodies and minds are able. We stigmatize those whose struggles are visible, conveniently forgetting that we each have our own struggles, too. **The artificial disability of race compounds this unequal treatment, making children who occupy the identities of both Black and disabled the most vulnerable.**

How do we determine which students are worthy of a quality education? And why do we value certain students' educational—and life—trajectories over others? The answers to these questions are systemic. They are rooted in ideologies of racism and ableism and enforced by practices that degrade the communities in which little Black kids learn, live, and play. This essay seeks to address this purposeful degradation—and subsequent erasure—of those who are both Black and disabled from society. Why is it that we have grown comfortable with alienating those who most require our attention?

Black disabled students are uniquely disadvantaged by the legacy of segregation in the education system. While disabled students struggle to procure adequate treatment and fair placement, Black students are more likely to experience hyper-surveillance and resource-poor institutions because of systemic racism. Students who are both Black and disabled must grapple with both of these obstacles. Applying race to the study of disabled students' experiences permits the use of intersectionality in an underemployed way.

> **We often consider intersectionality in socioeconomic status, gender, and race, but less so when it comes to disability. Occupying the statuses of both disabled and Black exacerbates the already difficult processes of identification, treatment, and placement for disabled students through increased tracking, surveillance, and segregation.**

Historically, the status of disabled individuals in the United States has been marginal. Throughout the 19th and much of the 20th century, disabled individuals were confined to institutions and often subject to sterilization (Pew Research Center, 2016). In keeping disability separate from society, disabled people were denied their personhood and agency. Indeed, "the fate of many individuals with disabilities was likely to be dim...In 1967, for example, state institutions were homes for almost 200,000 persons with significant disabilities. Many of these restrictive settings provided only minimal food, clothing, and shelter. Too often, persons with disabilities... were merely accommodated rather than assessed, educated, and rehabilitated" (US Department of Education, 2010). It was only in 1975 that the Education for All Handicapped Children Act was written into law, providing equal access to free public education for disabled children. Most recently, in 1990, the Individuals with Disabilities Education Act (IDEA) allowed for the inclusion of parental voices and the development of Individual Education Plans (IEPs). Today, schools' accreditation and grading processes include their IDEA compliance. IEPs must be detailed, comprehensive. Schools are also required to submit demographics of students served under IDEA to their state departments of education and the federal department of education. These demographics include grade level, disability type, and racial identity. In American schools, **Black students lead all racial demographics in students receiving special education services under IDEA (National Center for Education Statistics, 2018).**

Today, many of American schools are nearly as racially and socioeconomically segregated as they were before Brown ● (Breslow, 2014). Over 2 million Black students attend schools with 90 percent racial minority students (Cook, 2015). The United States, home of educational segregation, maintains this title chiefly because of housing segregation and geographic isolation. Although the existence of segregation itself does not necessitate poor outcomes for Black students, it does lend itself to greater resource disparity. These resource disparities translate to academic disparities very early in children's lives. In a U.S. News & World Report on school segregation post-Brown, reporter Lindsey Cook writes that "by age 2, disparities already show between Black and white children. Fewer Black children demonstrate proficiency in development skills such as receptive vocabulary, expressive vocabulary, matching, early counting, math, color knowledge, numbers and shapes" (Cook, 2015). These disparities clearly become exacerbated when children enter schools, with significant consequences for disabled Black students. For schools with less financial capital, special education services can become altogether non-existent.

● Brown vs. Board of Education declared school racial

Just as Black students are less likely to have experienced teachers, disabled students are less likely as well (Holdheide & DeMonte, 2016). In fact, "teacher shortages may be the most acute problem in special education," as "47 states reported shortages of special education teachers" for the 2013-2014 school year (Holdheide & DeMonte, 2016). It is thus evident that structurally Black disabled students experience a double disadvantage by the current education system.

Beyond this, the definitions of ability and whiteness have been virtually inseparable from slavery to the present-day. Coupled with the powerful persistence of racial stereotypes, insidious measures of 'intelligence' taint school-level interactions today. For example, IQ testing has been hugely influential in how we conceive of both race and intelligence. Alfred Binet developed the average IQ from a sample of white, middle-class children, chosen for the test specifically because their teachers deemed their performance as "average" (Siegler 1992). But it is worth asking: average for whom? The children tested had a very specific set of cultural knowledge. They also had been subjected to formal instruction, resulting in an academic skill-set much greater than children with less privilege. So, was their success on Binet's test due to ability or racial bias? Binet's test was originally conceptualized to identify students lagging in school, and eventually provide them with remedial services. Instead, it manifested into a means of perpetuating the subjugation of those already living in the margins.

In schools across the country, Black children are overrepresented in special education programming whilst white children are overrepresented in gifted education (National Center for Education Statistics, 2018).

The overrepresentation of Black students in special education is a widely-recognized issue in the field of educational policy (Klingner et al., 2005). But what exactly happens to Black students when schools place—or funnel—them into the special education system? Immediately, these students receive a label, and this stigmatized label follows them all throughout their educational careers. We have heard of the term "school to prison pipeline," but a "special education to prison pipeline" exists in our society as well. The US—despite making up only five percent of the world's population—accounts for twenty-five percent of the world's prisoners (Bronson, 2015). Of America's ridiculously large prison population, sixty-one percent are people of color. Of that population, roughly thirty percent possess a disability (Bronson, 2015). The term "school to prison pipeline" refers to the contact that students have with the carceral system as a result of certain educational practices, like over-policing and zero-tolerance policies. For kids who may have behavior or emotional issues due to a disability, this pipeline is even more prominent. With this in mind, can we trace this population back to their educational experiences? And if so, what does that say about the special education services—or lack thereof—that these people receive as children?

To equip Black disabled students with the same skills that white, typically-developing children receive is still a disservice. Rather than equality, we should be working toward equity. Whereas solutions with equality in mind necessitate sameness, equitable solutions mandate fairness. This requires radicalism. In Michele Foster's Black Teachers on Teaching (Foster, 1998), one experienced teacher stated: "I do talk about the ills of capitalism, but I don't use those words. We discuss why it's wrong to go to school just to make a lot of money or why it's wrong to sell drugs to make money" (Foster, 1998, p. 179). Since then, I would contend that teaching has become even more political, particularly when teaching the children for which this work is written. We do our students a disservice when we claim they are too young or too inexperienced or too abnormal to comprehend things that impact us all. In a world that outright demonizes and "others" children who are both Black and disabled, educating them and teaching them their rights is the practice of freedom.

Crossing Cultures: My Experience as a Hearing Foreigner in a Deaf World

Hillary Chua

Hillary is a master of Bioethics candidate at Harvard Medical School who will be graduating in May 2019. She first became interested in Deaf culture when she witnessed a song-signing performance in 2012. Five years later, she joined a church with an unexpectedly large deaf and hard-of-hearing community and became a sermon note-taker. Many members of this community use sign language and identify as being culturally Deaf. This cultural identity is marked by the term “Deaf with a capital “D.” After attending weekly dinners with the Deaf, Hillary felt compelled to learn sign language. In Fall 2018, she moved to Boston for her master’s program. This story is about her experience of becoming involved in the Deaf community and the peculiarities of entering an American Deaf space as an international student.

What does a deaf person's inner voice look like? How do the deaf experience the monologue of self inside the mind? The answer eluded me until one day, shortly after I first moved to America, I awoke from the most unexpected dream of my life.

In my dream, I saw some of my Deaf friends signing to me. Though I was asleep, I vividly read their signs and I sensed my hands shifting to form words in reply.

Unbelievably, I had dreamt and thought in sign. As a hearing person who had only become involved in the Singapore d/Deaf community the year before, this revelation came as a pleasant surprise.

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"Don't forget how to sign!" Before leaving Singapore for graduate studies in Boston, a Deaf friend imparted me with this solemn piece of advice. "I won't," I vowed. Yet six weeks after arriving in America, I still hadn't met anyone who could sign. My fingers itched to communicate in sign – I didn't care with whom. Back home, I had the freedom to sign during weekly worship in church, alongside d/Deaf congregants and fellow hearing allies. In my new American church, I had to keep my hands to myself. Not being able to sign impaired me of an entire faculty of expression. To my chagrin, the Deaf Awareness Club on campus cancelled their American Sign Language (ASL) classes that semester. Things were looking bleak, but the dream jolted me with a renewed sense of determination. No more sitting around and waiting, I thought to myself. After some dogged online sleuthing, I discovered and fixed a date to attend Deaf Night Out (DNO) in Boston.

'What was I thinking?' The chilling loneliness of walking down an unfamiliar street on a cold, Boston night had me second-guessing myself. Maybe heading to DNO alone, in a foreign country, without telling anyone, wasn't such a good idea. Yet the moment I stepped into the bar, my fears were whisked away. At last, I was surrounded by vibrant, signing people. As luck would have it, the first Deaf person I met, a guy named Michael, had a hearing mom who willingly acted as my interpreter. Just like me, she used Signing Exact English (SEE-II).● This was the sign system used by the d/Deaf community in my church in Singapore. Michael's mom was my crutch for understanding the Deaf Bostonians. I soon discovered that the Deaf-hearing divide wasn't the only barrier I had to cross that night. When I introduced myself to one old man, he asked me if I was from China. "No, I'm from Singapore; an island near Malaysia," I signed. He looked at me, puzzled. Even Deaf Americans think that Singapore is part of China, I chuckled to myself. In the spirit of multiculturalism, I learned signs like "Thanksgiving" and "Disneyland" from various conversations, which drove home that I was in America. One unfamiliar sign lingered in my mind for days after the event: A Y-shaped hand sliding across an open palm. That looks like the sign for 'new', I thought, before putting two and two together. Oh! He meant 'New York'! My belated eureka moment was one that I cherished alone.

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● Signing Exact English (SEE) is a sign system that manually represents English sentences in signs.

"I serve in the Deaf ministry in my church", I explained to a friend. The humid Singaporean air clung to our skin as we lunched outdoors in the central business district. As if it couldn't get any hotter, a car spouted exhaust as it zoomed by. I shifted uncomfortably in my office dress. Meanwhile, my friend gawked at me in horror. "Deaf, not death", I retorted, glaring at him. You clearly have something in common with them, because you obviously can't hear. Throwing that jibe was too tantalizing to resist. Yet much later, I learned that using the word "deaf" in that way could amount to ableism by equating disability with deficit (Lewis, 2019). I was ashamed of myself. This was one of many failures in my endeavor to be an ally of the Deaf.

***

In December 2018, I finally met a Deaf woman at my church in Boston. After watching us converse, her interpreter remarked: "You know much more sign than I gave you credit for." Though it was a compliment, the bar was low. The interpreter explained that most people she met who claimed to know sign could fingerspell their names at best. As if to discredit her praise, the next Sunday I forgot the sign for "tomorrow". The Deaf congregant had to sign it several times and agonizingly voice the word before I finally got it. By then, I had 1.5 years of signing under my belt, but was still forgetting my basics. What a loser I was.

***

The sting of shame threw me back to my first visit to the ASL table in Lowell Hall at Harvard. Students met at this language table to practice their ASL. Without knowing any ASL I entered an unvoiced, group conversation in ASL for an hour. I was utterly lost. The letters "a" and "t" in the ASL alphabet were different. Some signs looked similar to SEE-II except that they weren't initialized ●● (e.g. "doctor" and "live"). Other signs were completely unrelated (e.g. "history" and "London"). To communicate, I had to pick up ASL on the fly and translate my thoughts in real time. By the end of the hour, I was overwhelmed by the gulf between what I did know and what I needed to know in order to communicate with the Deaf.

***

"Now you know how I feel when I'm with a group of hearing people," my friend Sheryl observed. This was in Singapore, around October 2017, and I had just experienced reverse dinner-table syndrome ●●● as the only hearing person at a dinner with Deaf people from church. Thankfully, Sheryl, who uses a cochlear implant, interpreted bits of the conversation so that I wouldn't be completely lost. Despite having felt out of place, I proudly took home some uniquely Singaporean signs: "Nasi lemak" and "Hainanese chicken rice." These were signs for food, of course. In hindsight, this venture beyond my comfort zone marked the beginning of my true involvement in the Deaf community. Before then, I had kept my conversations with the Deaf to a minimum and huddled with the hearing interpreters after church. Little did I know that one year later, I would be taking an even bigger leap by attending Boston University's ASL Ball.

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●● Initializing refers to signing with a handshape that forms the first letter of the word.

●●● Reverse dinner-table syndrome refers to the experience that many d/Deaf people face of being left out of hearing people's conversations, e.g. at dinners with hearing relatives (Hauser et al., 2010).

At the ball, I had to sign voicelessly for hours without an interpreter in a dazzling hall full of people. My eyes, facial muscles, arms and hands worked doubly hard to compensate for the loss of my voice. After the ball, my upper body crumbled from exhaustion. I cringed as I recounted all words I had mis-signed. Yet on the whole, I was elated. I had met a Brazilian student who was doing his PhD in robotics, exchanged views about mainstreaming deaf children in Singapore and America, and received news about the California wildfire. All this information was gleaned from signs. The ASL Ball broke the boundaries of what I thought was possible. I, a hearing foreigner, was now thinking and communicating in sign.

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Despite my slowness to learn, faux pas and mistakes, I am starting to accept that it comes with the territory of crossing cultures. Although the burden of shame sometimes makes me question myself – *What's the point of all this effort? Do the Deaf even care? I hardly meet Deaf people outside of church anyway!* – two things keep me going. Before I left for Boston, a hearing friend shared that when he first started learning to sign, a child of deaf adults (CODA) judged that his signs were sloppy. "She told me I could never become an interpreter," he recalled. Instead of succumbing to defeat, he worked to prove his critic wrong. Today, he is one of just nine professional Singapore Sign Language (SgSL) interpreters in my country. Perseverance reaps rewards. Yet I have a greater reason to keep learning sign. A few weeks after my visit to the ASL table at Lowell Hall, I bumped into one of the proficient ASL users at an unrelated event. This was our second meeting, but my first time encountering his voice. As it turned out, he was hearing and from Singapore too. Not only that, but he had begun his sign language journey, years before me, in the same church I had come from. In fact, he knew the very friends I was missing and had been dreaming of. What were the odds?

I was struck by the power of sign language to unite a community and enrich the lives of the people it touches. Even abroad, I was not alone. I was not alone in choosing to learn sign language and step into the shoes of the Deaf.

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Soon, I'll be graduating and returning to Singapore. I can already imagine myself reconnecting with old friends, embracing the awkwardness of reintegration, and sharing stories about Boston in Singaporean signs. Perhaps, when I'm home, I might even dream of America in sign.

Viewing life through a different lens: An interview with my mother

Haneen Abdo

Haneen is a graduate student at the Harvard Graduate School of Education, specializing in Technology, Innovation and Education. She is originally from Palestine but lived, worked and studied around the Middle East before moving to Boston. In this piece, Haneen shares a story of her mother, Ramz, who lost her vision during when she was 40. In this interview, Haneen highlights the hope and challenges faced by a blind woman who is determined to live life to the fullest.

Almost fifteen years ago, my mother, Ramz, was diagnosed with Retinitis Pigmentosa (RP). RP a disease which causes the retina to degenerate, progressively instigating the gradual yet steadfast loss of sight. As my mother saw less and less of the world, her perception of the world changed – and so did mine.
Today, her vision loss has deteriorated to a point that she cannot see anymore.

My mother's condition paved the way for her to embark on a journey of courage, grief, laughter, anger, self-love and wisdom. She told me, "My loss of sight made my vision of the world much clearer."

You see, my mother is a fighter; she comes from a special breed of fighters who refuse to show weakness and do the exact opposite of what others expect them to do. She is the type of fighter who wakes up in the morning, puts on the most beautiful and colorful dress, wears makeup and high heels. She frequently visits the hair salon (more than she probably should – or anyone should, for that matter)! She is beautiful and loves to sing. She has tons of friends who adore her. She travels, sometimes alone, when she wants to. She loves to swim (and tan). She seamlessly builds a network – and always gets upgraded at hotels (a mystery I have never decoded)! People around her are frequently astonished by her persistence to live life to the fullest despite her disability; one of her family members once told me, "another woman who has her disease would be depressed at home and would have no life – I don't understand your mother." It's very interesting how some people react; they are surprised – sometimes disappointed -- when someone does not fall or fail when they are expected to.

Well, she proved them wrong, over and over again. She changed the trajectory that society set for her. Nevertheless, her journey has its own challenges. The challenges present themselves in two forms: the high-level sentiments and the details. I asked my mom if she would agree to be interviewed and featured in this publication, and she gladly accepted.

Haneen: Mama, what would you say are the hardest days?

Ramz: "There are moments when I wish I could see, even if it's just for a few seconds. When my twin sons were born, I never got to see them properly, I just heard that they were very beautiful. I had to sit there and hear others praise their beauty in front of me." She paused and then continued, "another moment I will never forget is when my daughter got married. I was sitting with her in the room before the wedding. I ran my hand over her face and wished I could get a glimpse of how she looked that night – it's not fair that everyone got to see her clearly except me". I could hear despair in her voice. She then concluded her answer by saying, "I wish I can see what you look like now."

Haneen: What are the daily things that bother you?

Ramz: “Well, I hate it that I sometimes have to rely on people. If I drop something or lose something, it’s so difficult.” She then says, with a laugh, “The worst thing is when I drop and break my cup of coffee and there is no one around! I begin to feel like I am the subject of a suspense scene in a movie. Another thing that frustrates and saddens me is when one of my children is hurt and I cannot help – it’s mentally crippling.”

Haneen: What has all of this taught you?

Ramz: “It taught me that I can never let anything stand in my way, I have to make the best out of things. That, even if I have to work twice as hard, I will always strive to be independent.” She then started bragging about how she mastered using her iPhone and how she can order an Uber by herself. She then continued, “I learned that life gives people some things, but also takes away other things and one needs to be strong and enjoy what one has. Imagine you really want steak but you go into the kitchen and you only have the ingredients to make pasta – make pasta and ENJOY it.” She hates pasta, but she loves that analogy.

Haneen: If you could tell people one thing, what would it be? How about young people with disabilities?

Ramz cleared her throat and started speaking with a proud tone. “Don’t treat people who have a condition or a disability with pity, they may very well be much happier than you are! Just be kind and human. Don’t make their lives more difficult with your intruding inquiries or astonishment about what they can achieve despite their disability. Your words and actions can be very demeaning and hurtful; be careful.”

> **“My message to young people who are diagnosed with any disability is: don’t be sad; I wasted a lot of time feeling sad for myself and it got me nowhere. Be proud and focus on what you already have. Be thankful. Don’t let anyone tell you what your limits are and what you can or can’t do. [You will have] hard days; [you will have] great days too – just like everyone else.”**

Growing up, my mother’s illness was the main source of heartbreak in my life, until I realized it doesn’t matter what her condition is, she knows how to be happy.

One day, as we were both walking on the beach back in Dubai, I started complaining about my job and my life. A few minutes later she said, “You know, Haneen, I actually feel very lucky. I know I cannot see the sea, but I can smell it, I can hear it, and I can feel it. Do you know how many people are unable to come here and enjoy what I am enjoying?” I remember thinking, “My God, she actually feels lucky, and here I am complaining about my silly worries.” I felt very small. Just as not all those who wander are lost, not all those who don’t see have no vision.

Reconsidering ‘Disability’ and ‘Merit’ in Higher Education

Nikita Andersson

Nikita is a student at the Harvard Graduate School of Education, where she will be graduating in May 2019 with a Master of Education (Ed. M) in Technology, Innovation and Education. Prior to joining Harvard, Nikita studied Modern History at Magdalen College Oxford. Nikita became increasingly interested in learning disabilities when she was identified as having dyslexia in her first year of undergraduate studies. At Oxford, she researched and wrote about the history of dyslexia in the United Kingdom, earning her the Gladstone Prize in 2018. She believes strongly that higher education needs to entrepreneur inclusive norms and set a positive example for society. In this piece, she explores the connection between meritocracy and disability in higher education.

Ableism is defined as "a pervasive system of discrimination and exclusion that oppresses people who have mental, emotional and physical disabilities... Deeply rooted beliefs about health, productivity, beauty and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities...fall out of the scope of what is currently defined as socially acceptable" (Rauscher & McClintock, 1997, p. 198).

On the 5th of March 2019, MP for South Shields, Emma Lewell-Buck was quoted saying "we need a cultural shift in the way we see specific learning difficulties...These things are led from the top and they filter down and shape how society views people with disabilities" (Beater, 2019). Echoing this sentiment, elite educational institutions need to take a leading role in challenging damaging stereotypes about disabled people. Since universities are "likely to remain the seed-beds for tomorrow's politicians and policymakers, the ramifications of a lack of critical approaches towards ableism should not be underestimated" (Bolt, 2007, p. 357). If they fail to do this, they are "limiting, diminishing and negating potential... the result of which is damaging to the whole" (Bolt, 2007). By taking a critical lens to ableist university cultures, academics can send a strong message to society.

Research in the field of disability studies has suggested that individuals' educational and professional outcomes are significantly affected by perceptions of their disability (Armstrong & Humphrey, 2008, p. 1). Therefore, recognizing disability as a social construct is fundamental to fully understanding the experiences of students in higher education (Lawson, 2001, p. 203). Constructions of disability are intimately tied to culture and, in particular, our cultural definition of "ability", "intelligence" and "merit" within educational settings (Dudley-Marling & Dippo, 1995, p. 413). Yet, universities, along with other spheres of society, uphold narrow conceptions of "intelligence" and "merit" that marginalize individuals who do not fit within the "norm"●. More than this, policymakers fail to acknowledge the implications this holds for disabled students and continue to use the language of "meritocracy" to justify fairness. This essay interrogates cultural and social definitions of "merit" in higher education, arguing that they are particularly damaging to individuals with disabilities.

● I define the "norm" as White, male and able.

Finally, it concludes by suggesting a few courses of action that universities might take to address this problem. Rather than focusing exclusively on providing supports for disabled students, universities need to radically change how they value "merit". By exploring these issues in depth, this essay brings a new perspective to conversations about disability and inclusion in higher education. Although I have focused on evidence from the United Kingdom, I believe that many of the points made will be relevant in other global educational contexts.

Problematizing Definitions of "Merit" in Higher Education:

In January 2019, the British Universities Minister Chris Skidmore declared that "no-one's background or circumstance should hold them back from the opportunity of a university education and there is no reason why disability should be a barrier to fulfilling someone's potential" (Department for

Education, 2019). His calls for success regardless of "background" or "circumstance" follow increasingly popular trends to make Britain "the world's great meritocracy" (Littler, 2017). Indeed, Prime Minister Theresa May has asserted that she wants "Britain to be a place where advantage is based on merit not privilege...where it's your talent and hard work that matter, not where you were born, who your parents are or what your accent sounds like" (Littler, 2017). But what exactly does it mean to judge someone on their "merit?" What is "merit?"

According to the Cambridge Dictionary, "merit" is defined as "the quality of being good and deserving praise, or a good quality" (Cambridge Dictionary, 2019). This somewhat vague definition highlights a deep social understanding of what it means to be with "merit" and without. In fact, how we define "merit" is highly subjective, and can be easily manipulated. As sociologists argue, "merit cannot be taken face value, as a measure of the worth of a person. It is better seen as a cultural artefact" (Madan, 2007, p. 3047). Nonetheless, society continues to use and accept the language of "merit" as an accurate way to rate people. Indeed, on a webpage entitled "Applicants with Disabilities" the University of Oxford emphasizes that "all applications are assessed purely on academic merit..." (Oxford, 2019).

When culture is defined as a process of shared meaning-making between individuals and the institutions around them, "merit" is inherently imbued with structural and individual power dynamics. **Compounded by societal views of what is considered "meritorious," in higher education what qualifies as "merit" is further decided by elite academic institutions. Those at the top effectively shape understandings of what it means to "succeed," relegating marginal voices in this process. "Merit" can thus be intimately bound to social inequality and injustice**.

For example, American historian, Lani Guinier, demonstrates this through an expose into Harvard's decision to define "merit" as "well-rounded character" to control and reduce the number of Jewish students accepted in the 1920s (Guinier, 2015). How "merit" is defined and who defines it within a social context is often highly problematic. Relating this back to students with disabilities, the meaning of "merit" in higher education can have serious implications for individuals hoping to "succeed" in structures that place narrow social boundaries on what this even means.

Impacts for Students with Disabilities:

But how exactly are definitions of "merit" failing students with disabilities? In its current definition and cultural reproduction, "merit" directly clashes with ingrained social understandings of disability. Harvard Education Professor, Thomas Hehir, explains this, noting that individuals and institutions often carry ableist assumptions that students with disabilities cannot achieve as highly as their non-disabled peers (Hehir & Katzman, 2012, p. xii). Ingrained low expectations result in the direct devaluing of an individual. In higher education, this devaluing can take several insidious forms, yet it is particularly stark when students with disabilities outperform nondisabled peers. **When marginalized students challenge power dynamics, they experience a backlash. For example, individuals who use accommodations for their disability might be accused of "cheating" or being "lazy" and not completing the assignment "properly," undermining their academic identity and perceptions of their own merit.**

Furthermore, students with disabilities are sometimes subject to direct challenges to their academic and disabled identities at the same time. Kaiya Stones, a former student at the University of Oxford, explained that she was told she could not really be disabled and be at Oxford (Beater, 2019) – a statement that has also been directed at the author of this essay. Similarly, Laura Schifter, a professor at Harvard Graduate School of Education, recalls accusations that she "couldn't go to Harvard and really have dyslexia" (Schifter, 2016). She explains that "it's really hard to admit to people that you have dyslexia because you never know how they will respond...whether they will think less of you... or whether they will think that you are not smart" (Schifter, 2016).

This suggests that social constructions of "merit" do not view intelligence and disability as compatible. Students with disabilities face a glass ceiling with regards to how much they can actually 'achieve'.

As a result, many individuals with invisible disabilities choose not to disclose in higher education to avoid discrimination (Hehir, 2015 p. 3). Whilst universities do not deny students entry to university because they have disabilities, the discourses operating within higher education often implicitly urge students with disabilities that covering it up is preferable if possible.

The experiences of students, whether they choose to disclose their disability or not, are significantly shaped by cultural reproductions of "merit" within higher education. Comments from university students with disabilities reveal that the social paradox is frequently internalized even if direct verbal attacks are not made. When deciding whether to commit to higher education in 2011, one student noted "the biggest issue going into university is self-esteem [and] not [feeling] as capable as other people" (Aimhigher Report, p. 35). Although increasing academic and financial supports have been a helpful policy, universities have critically failed to address underlying ableism. This has resulted in the embodiment of certain cultural expectations of who can succeed and who cannot. Thus, students "begin to believe that their placement in these groups is natural and a true reflection of whether they are 'smart', 'average' or 'dumb'" (Hatt, 2012, p. 441). Effectively, "intelligence" behaves as a culturally produced phenomenon that students eventually embody through their practice and discourse (Hatt, 2012, p. 442). Reflecting on his experience having graduated from the University of Bristol, one student believed that "[he] could have enjoyed [university] more were it not for [his] dyslexia...Mentally, [he] couldn't shake the fear of failure..." (Hall, 2019). For this student, "mentally" he was always afraid that his disability made him inherently predisposed to "failure."

Finally, this paradoxical relationship between "merit" and disability is not only damaging to students in higher education, but also to academics. In their recent article, "Ableism in academia: where are the disabled and ill academics?", Brown and Leigh argue that "in the long term, academics need to be seen not as the privileged elite sitting in the ivory tower of scholarship, but as individuals who, when it comes to navigating workplaces, may also be marginalized and whose voices may remain equally unheard" (Brown & Leigh, 2018, p. 988).

> **In a society that is obsessed with league tables, norms and achievement, individuals with disabilities are discouraged from entering professions that they are typically 'not supposed to do'. This has resulted in the dramatic underrepresentation of academics with disabilities**. (Brown & Leigh, 2018, p. 988).

Furthermore, academics with disabilities face the same glass ceiling that students do. Brown and Leigh note that "they are not taken seriously or seen as academics in their own right, and that their achievements and publications are considered through the lens of their disability status" – a status that is socially produced as inferior. As a result, "they may be expected to trade off their identity," further marginalizing the space for disability in higher education (Brown & Leigh, 2018, p. 988).

This essay has highlighted an endemic and overlooked problem in higher education, and I suspect that this problem is not exclusive to universities in Britain. Narrow cultural definitions of "merit" have a significant impact on the perception and experience of disability in higher education. Diversity and inclusion initiatives frequently try to address underserved students by creating support systems to help them achieve and adhere to these exclusive standards. However, institutional leaders should instead be more critical of what they view as "meritorious." One suggestion is to expand definitions of "merit" to be more inclusive and to embrace pedagogical methodologies such as Universal Design for Learning. In addition to this, if cultural ableism in higher education is to be challenged, then leaders need to change the discourse around disability. Rather than viewing academia on disability as marginal, it needs to be valued equally and integrated further into other areas of study. For example, historical academia is highly regarded when it draws upon gender and race studies; the same should also be true for disability studies. One way to approach this is to increase the representation of disability scholarship in mainstream subjects. Academics are viewed by society and by students as role models of intelligence and excellence. If professors from a variety of disciplines were to highlight the contributions of disability scholarship and the disabled community, stereotypes will change.

Troubled

Tailor S. Dortona

Tailor Dortona is a Global Diversity & Inclusion specialist and current master's of Public Policy candidate at the Harvard Kennedy School of Government. Prior to attending HKS, Tailor had the honor of serving the Obama Administration's Special Advisor for International Disability Rights, Judith Heumann. In that role, Tailor was afforded the opportunity to travel the globe and consult with both foreign governments and civil society on the creation of inclusive education and labor policies. Tailor has additionally served as an Equal Employment Specialist with the US Navy and as a Research Analyst at the Education Advisory Board. In both roles, Tailor focused on diversity recruitment and conducting barrier analyses to identify institutional roadblocks hindering the ability for disabled persons to thrive in the classroom and workplace. Through the Gilman Scholarship, Tailor lived in Chengdu, China to conduct field research with the Chengdu Disabled Persons' Federation and to establish a dialogue on inclusive education between the US and a Chinese government think-tank. Tailor's original research has since been presented at three national conferences and published in journals of literature and psychology. Tailor's passion for equity and inclusion stem from her own experiences as a proudly disabled, LGBTQ+ community member.

Photo Description: A massive, three-story brick building with broken windows throughout looms behind unkempt shrubbery and long dead grass. The building's foreboding façade is juxtaposed with an intensely white sky, devoid of clouds or anything else.

As an international disability rights activist, I have witnessed injustices perpetrated against the disability community that Americans couldn't possibly imagine. Sweatshops where the laborers are barred from speaking, schools with padlocks on the front door, alleyways transformed into a city's only affordable, accessible housing. But the United States has its own dark history—a history unbeknownst to most but etched into the brains of the millions who were forced to endure life in an institution. Often referred to as insane asylums or mental hospitals, institutions were society's government-funded solution to "hiding" the disabled population. Like a prison with no hope of release for good behavior, an institution is as good as a death sentence. The experiences of their residents are unfathomable, as institutions were hotbeds of human rights abuses. The right to human treatment in institutional settings was not recognized by the US Supreme Court until 1982. And while the practice of mass institutionalization has faded, many of the physical structures remain.

This photo essay depicts Forest Haven Hospital, once home to thousands of disabled children and adults, complete with dormitories, food hall, and a morgue. Located in Maryland and sponsored by the Washington, DC Government, a judge ordered Forest Haven's closure in 1978 after the reported cases of abuse, wrongful death, and budget cuts had piled too high to justify its continued existence. The unmarked graves of Forest Haven's victims lay just behind its administrative building, where unsuspecting families dropped off their loved ones in hope of providing them with affordable care. Doctors forged death certificates to ensure that nothing but "accidental overdose" and "cause of death: unknown" made their way into the files. So while Forest Haven's operations may have ceased, its transgressions must never be forgotten.

They may be called hospitals, but make no mistake, their intentions were not benign; they shamed families into locking up their loved ones in the name of creating a more perfect society. But I know what lays beyond those walls. And now you will too.

Photo Description: Framed by a dark door frame, this vertical image provides a glimpse into a dishevelled room containing nothing more than a single metal chair. The walls and ceiling reveal exposed sheetrock and wood, as their paint has been stripped away in large patches. The floors are blanketed in unidentifiable debris and rocks. Light floods in from a single window at the far end of the narrow room.

Photo Description: A long, metal drawer packed with oversized notecards rests atop a debris covered desk. The alphabetized notecards have been wedged apart, revealing a card filed under "H." The card is titled "D.C. Children's Center" and reveals the name, number, and date of birth for patient Hunt, John.

Photo Description: Looking up at a clock hung upon a once blue wall. The paint is overwhelmingly chipped, and the face of the clock appears to be melting off its circular, metal body.

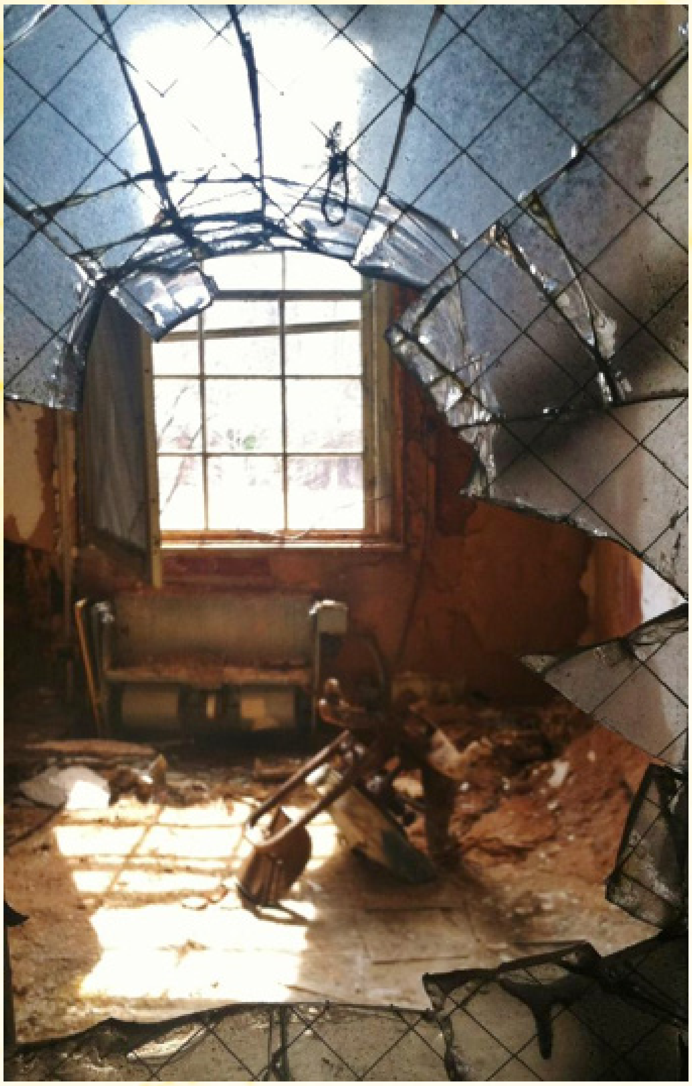

Photo Description: Patterned glass has been smashed through, producing jagged edges and an oblong peephole. The room which lays beyond is blurry, but clearly empty, except for a large pile of dirt and a toppled rolling chair.

Photo Description: A small, rectangular poster clings to a dirty cement wall. Peeling and ripped, the fading children's poster reads "Valentine, Be Mine" with a large, arrow-pierced heart at the center.

Photo Description: In the middle of a large, empty room sits a massive, bright blue, padded wheelchair whose thin, back wheels sit far behind the seat. The chair can solely be pushed via a metal bar at the back. Its padded back has been vandalized, now reading "Angel Mike" in black paint.

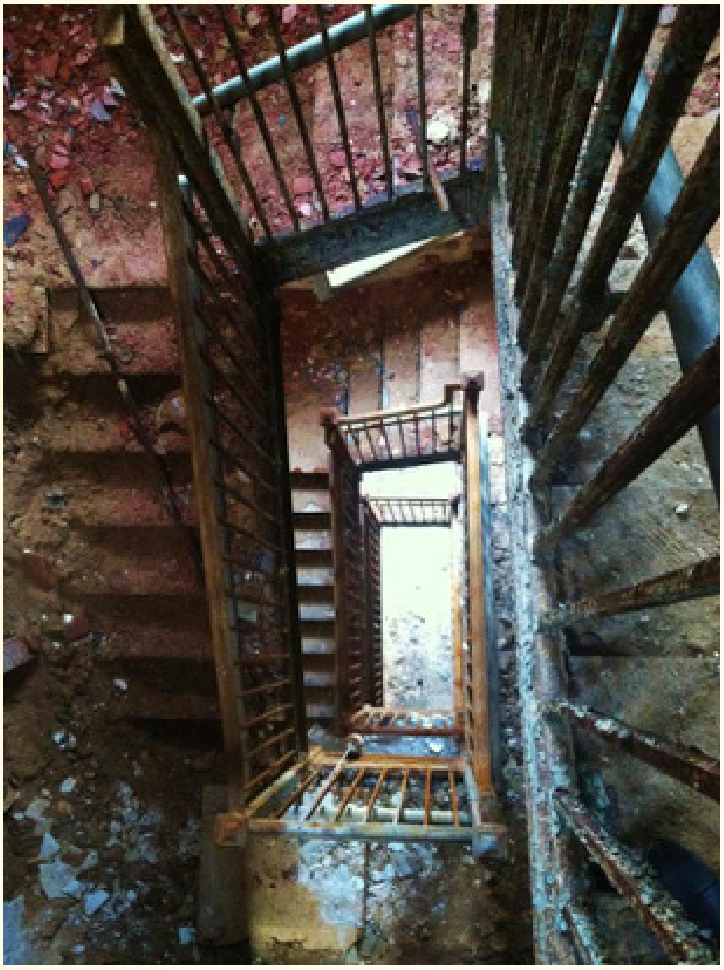

Photo Description: An aerial view of a four-story winding staircase. Deteriorating paint reveals dark, eroding metal.

Photo Description: Intense, white light floods in from behind a piece of white paper taped to a patterned, glass window. The window is part of a door which leads into a patient dormitory, whose metal bed frames peek from behind the paper announcement. The paper is headed with an outline of a dove and reads "Good Morning, this is GOD! I will be handling all your problems today. I WILL NOT need your help. So have a good day."

Good Morning, this is GOD!
I will be handling all your problems today. I WILL NOT need your help. So have a good day.

Photo Description: A black and white mural depicts the faces of Rosa Parks, Malcolm X, Dr. Martin Luther King Jr., Frederick Douglass, and Harriet Tubman. Above the civil rights leaders appears the word “Spirit” and below reads “AND AGAIN I RISE.” The wall’s ambient paint is chipping, but the mural remains mostly intact.

Photo Description: Soiled mattresses are piled high against a dormitory wall displaying a playful jungle mural.

Photo Description: A bright orange wall features iconic cartoon character Roadrunner beside a large clown balancing on a tightrope. The clown is gazing up at a comically small, pink umbrella he is holding. The painted umbrella is perfectly positioned beneath a large hole in the ceiling.

Photo Description: A small stack of white papers with unreadable, handwritten scribbles lays on an angle atop dark, rocky pavement. A small plastic doll with a matching orange hat and dress is resting besides the papers. Her large, blue eyes are angled towards the print.

Photo Description: A tiled wall is vandalized with competing messages. The original message, painted in black reads "SHE BLEEDS FROM EVERY FUCKING HOLE." A second message in light blue covers the word "bleeds" with "learning" and "hole" with "struggle." The new, black and blue message reads "SHE LEARNED FROM EVERY FUCKING STRUGGLE."

That’s what makes you beautiful: privilege, ableism and desire

Allan Hennessy

Allan Hennessy is a human rights lawyer/advocate, a journalist at The Guardian and a Master of Laws (LLM) student at Harvard Law School. His advocacy comes from both the heart and mind. He studied Law at Cambridge University, graduating top of his year in constitutional, environmental and European Union law. There, he acquired the education and analytical equipment to fight for social justice issues in the courts. But his advance comes primarily from the heart, informed as it is by his life experience and struggles. Allan is a blind, queer Iraqi former refugee who grew up in one of Britain’s poorest council estates in London. His intersectional struggles are the foundation for his research. He is currently writing his thesis on how to make anti-discrimination law more intersectional. He is also interested in the politics of beauty.

In her thought-provoking lecture to students of the Fashion Law Lab at Harvard Law School earlier this year, the model and activist Cameron Russell offered a powerful critique of the fashion industry's ambivalence towards – and at times promotion of – sexism, sexual harassment, racism, modern slavery, animal cruelty and environmental damage. She outlined some of the efforts in the industry to combat these "social sustainability" issues; France has recently passed laws that require fashion houses and magazines to notify the consumer if a picture is airbrushed; in response to the #MeToo movements, a number of anonymous support lines have been set up for models who are the victims of sexual harassment. There was, however, a striking omission from Ms. Russell's furious critique: the overlooked plight of the disabled model.

Russell's omission is regrettable. It is regrettable because it is symptomatic of the problem that disability rights are often forgotten in the fashion industry's drive towards social sustainability.

The fashion industry is, of course, on an important journey towards social sustainability. There are a number of important passengers on the social sustainability train from Milan to New York via Paris and London: the environmentalists, feminists and race activists, for example. But the disability activists are nowhere to be seen on the carriage; they are being left behind on the journey.

Disability rights fall outside the definitional contours of social sustainability. But Russell's omission is understandable (but not justifiable) for two reasons. First, the statistics are instructive: disabled models are far and few between on the catwalk. They exist, of course; in 2016, blind models closed the Paris fashion show (Iheme, 2016); New York followed suit, with amputee and wheelchair users shattering stereotypes on the catwalk in style (Chung, 2015). Yet, those moments on the catwalk – moments that capture the resilience and strength of the human condition – are the exception rather than the rule. Ms. Russell gracefully accepted this when I asked her how many disabled models she had worked with during the course of her 15-year career.
Secondly, the fashion industry is a breeding site of ableism. Ableism is embedded in the system to its core. Enforcing and responding to social norms as it does, the fashion world glamourizes the conventional wisdom on beauty. That conventional wisdom makes no space for disabled bodies. What is sexy about wheelchairs, lazy eyes and muscle spasms? The pernicious politics of beauty dehumanize the disabled subject; our bodies are so often asexualised, our sexual desires laughed off or bludgeoned.

The 'disabled stereotype' does not speak of success or determination; it does not make room for outspoken and opinionated voices.

It demands that you stay in your lane. The disabled stereotype is subdued and helpless; it is characterized by pity and dependence. It cries for help, but otherwise only speaks once it is spoken to. It is devoid of sexual desire. It is asexual. And what fashion house would be interested in the un-sexy, the un-beautiful – the ugly?

As a microcosm of society, the catwalk is not where we must start in our drive towards disability rights and making disability 'sexy'. The law is also not the place to start, as I have written elsewhere (Hennessy, 2016); law is a blunt tool – it simply cannot extinguish the prejudice that festers in the minds and hearts of the masses.

Change will only come with a revolution in the mind and hearts of the consumer. One fashion house alone will not herald that evolution.

But the fashion house is a site of great power, and with that, of course, comes great responsibility. If Stella McCartney can inspire a vegan revolution in fashion, someone can get going on the disabled revolution. It is time the disability activists are given their ticket on the social sustainability train. Because we're worth it.

“But when you’re sick, you go to the doctor.”

Zina G. Noel

Zina G. Noel is an early childhood educator and policy analyst, concentrating on the socio-emotional development of young children (prenatal to five years old) in conflict and post-conflict settings. She strives to evaluate research-based models for “developing communities” around the world, including within developed countries, and strives to elevate the voices of practitioners and individuals from these communities. She is currently pursuing a master’s in International Education Policy at the Harvard Graduate School of Education. This essay delves into one person’s struggle to afford treatment for Cyclic Vomiting Syndrome: a rare, chronic, and invisible illness. In America, class privilege can be the difference between life and death.

I almost wrote about having a rare illness, and how doctors don't always know what to do, even in the best facilities in the entire world, and how that lack of knowledge often translates to very real harm.

I almost wrote about having an invisible illness, and how obtaining necessary care in formal medical settings often requires performative sickness from the very people straining to maintain normalcy.

I almost wrote about having a chronic illness, and how distinguishing the critical pains from the daily ones can often feel like a vexing puzzle; how much energy in the lead-up to an episode is spent just trying to know, "Is this an episode yet?"

I almost wrote about the American medical system, the lives thrown apart by its inadequacies, the families bankrupted by its exorbitant costs, and the companies that profit from that pain.

But because Cyclic Vomiting Syndrome (CVS) is rare – estimates are between four and 2,000 per 100,000 individuals – invisible and chronic, and because many of the people who have either pediatric or adult CVS reside within America, all those topics necessarily feed into a discourse on the ways in which economics and CVS intersect. More importantly to me, because CVS is rare, invisible and chronic, and because the American medical system is financially driven, the voices of people with CVS exist only in the margins.

In this essay, I hope to share just a fraction of their realities as I share my own story, and to offer validation for why people like me don't go to the doctor in life-threatening medical crises.

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When I turned 18, I became responsible for the medical debt that my parents, unable to pay, had left to me: $32,000 USD to be specific. Around the age of 12, I had started to have unpredictable and uncontrollable bouts of illness that rarely had any commonality other than vomiting. I would get pneumonia, and vomit. Strep throat and vomit. Menstruation and vomit. Prom night jitters and vomit. Aside from the immediate incidents of hospitalization, my mother – a nurse practitioner and nursing instructor – sought out diverse care that resulted in expensive medications, treatments and doctor visits which were not usually covered by our healthcare. I saw pediatricians, was referred to gastroenterologists, neurologists, and allergy specialists, and I consulted acupuncturists and homeopathic medicine. And while this all came with high financial costs, none of it really helped. My mother, raising two other children on the combined salary of her two jobs, struggled to find both the money and the time for these visits, but also for providing the amount of food that a child vomiting between 10-20 times a week required. My sister, after making a beautiful meal, once refused to share it because of the likelihood that I would vomit it up, noting that we didn't have the money for her to have it again anytime soon. I was hurt, but I understood.

But we got through, and at the age of 18 I packed up my bags and moved west for college; without a formal diagnosis, I assumed my health was just a cruel quirk and that if I wanted normalcy in this life, I would have to create it for myself. By the end of my freshman year, I was in a health crisis, hospitalized through final exam periods and quickly losing the weight and nutrients my body needed for survival. A family friend saw a late-night infomercial about this thing "CVS," and thought the description sounded like my sickness. Since the doctor was based in Milwaukee, WI, my hometown, I decided to take a semester off and see if Dr. Thangram Venkatessan and the Medical College of Wisconsin could help me finally find answers.

And she did. As a syndrome – a collection of shared symptoms – CVS is diagnosed by a process of elimination, and I spent that summer meeting with specialists, undergoing testing and providing personal and family history. By the end of the summer, I was diagnosed with CVS and began the process of developing a treatment protocol. First came an exclusionary diet, to see if any foods or drink were triggers for my episodes, which meant no dairy, no gluten, no trans fats or added sugars. It also meant specialty grocery stores, increased cooking time, and when I returned to college the next spring, a negotiation of the school's required meal plan. This diet was coupled with vitamins and medications: a cocktail of COQ10, L-Carnitine and vitamin B-6 paired with prophylactic and abortive medications. While the vitamins remained constant, I had to experiment with the various abortive medications while rotating through the prophylactics – this one caused depressive swings, while this one caused bone pain; I couldn't sleep with this one, while this other one shrank my appetite. I could no longer work full-time while attending school – yet the special diet, my vitamin cocktail and the various prescriptions, most of which were not covered by my student health insurance – cost around $1,000 USD per month. Each time I had to go into an urgent care or emergency room, I would incur another bill between $500 and $2,000 USD. It became impossibly expensive to stay alive, let alone to stay on top of my health.

But I wanted that life I'd dreamt of, or at least the opportunity to pursue it, and so I kept going. By my junior year I was able to manage well enough that I started working again, first part-time and then full-time. But since CVS was not covered by disability accommodations, I had to navigate conversations about the flexibility my health required, often drawing on Miserandino's Spoon Theory ● to explain why my available energy differed moment-to-moment, day-to-day (Miserandino, 2003). One employer joked after one of these conversations, that "this would be so much easier if you just had cancer." Again, I was hurt, but I understood.

But even with my employer-provided health insurance, simply obtaining the services I required was often a struggle. My specialized medications always required prior-authorization – because the insurance companies had to make sure that I really needed these medications – and I spent hours at the Walgreens counter pleading with pharmacists. Because my episodes occurred randomly and unpredictably, I was beholden to urgent and emergency care facilities where staff rarely knew what to do with me and often ordered unnecessary tests and expensive medications despite my protests. I earned too much to qualify for Medicare but couldn't see how I would be able to manage on disability support.

And then I moved in with my partner. White, resourced, male, and able-bodied, he had navigated life with an ease I had never considered for myself. But more than that, he was able to navigate the struggles of my life with an ease I never could have imagined. Suddenly, prior-authorization didn't matter, and, if I stayed in the car, he could walk out of the pharmacy moments later with my prescriptions in hand. Suddenly, urgent and emergency room doctors didn't need a background in CVS to trust his recommendations for what should happen. Suddenly, the $500 my six abortive nasal sprays cost was payable. Suddenly, it seemed I could not only stay on top of my health, but possibly outlive the early morbidity I had long dreaded.

As I became less fearful of my illness, I became more interested in the community that existed around it. I started participating in medical studies, joining CVS support groups, following hashtags on social media, and became a member of the Cyclic Vomiting Syndrome Association.

But when I began to engage with the community around CVS, I found that the commonality of the economic burden was as triggering as the photos of shrunken waists, hollowed eyes and IV lines.

Every day, a story filters into these forums about someone who's lost their job because of their illness, someone who can't afford their medications, someone bankrupted by treatment, someone feeding their family through food pantries, someone living on the streets caught in the cycle of inadequate disability support, someone fighting insurance companies even with the Affordable Care Act – because CVS is not necessarily a "pre-existing condition." Almost every day, someone wonders aloud to the groups if anyone else worries that CVS will kill them.

It hurts, but I understand, in a molecular way. I feel, daily, in my core of self, the immediate way class privilege has freed me from these worries. By the fact that I no longer fear going to the doctor, no longer dread the pharmacy line, no longer worry that an extra sick day stands between me and gainful employment or housing or travel. The illness is still a part of my daily life, but with just a bank account, I no longer fear my death from it. I no longer worry that it will kill me.

I do not know how we move from here. There are people far more versed in disability rights and healthcare policy and capitalist economic systems that work tirelessly and often without due credit or support to fight for a more just medical system. I am inspired by the activists who share their pain more openly than I do, by those who march to Washington and spend hours camped out in congressional and senate offices demanding the extension, or at least maintenance, of the Affordable Care Act, by those redefining what it means to have a disability. I am hopeful that the elected officials putting forth bills to restrict pharmaceutical costs and the medical professionals fighting for coordinated and patient-centered care have finally heard us.

But when my fellow citizens proclaim state’s rights to deny necessary health services, I wonder if they consider the millions of Americans with disabilities’ right to live. When my fellow citizens dismiss these political movements for fear of “death panels,”● ● I wonder if they realize that they currently sit on our death panels, ruling every day on the lives of millions of Americans with disabilities. When my fellow citizens argue that the free market will correct itself, I wonder if they consider how many Americans with disabilities will die in the meantime.

What I do know is that for every person born into class privilege, working towards it or, like me, accidentally stumbling into it, there are countless others doing their very best to survive. In the margins. On the street. In urgent and emergency and hospice care. And I wonder what all of us could be doing, how we could decide in every moment, every movement, every choice of every day, to help them thrive.

For more information about Cyclic Vomiting Syndrome, and how to participate in the fight, please see the Cyclic Vomiting Syndrome Association, http://cvsaonline.org/what-is-cvs/.

● The Spoon Theory describes the reduced mental and physical energy available to persons with autoimmune, disability, mental and other chronic illnesses, with “spoons” serving as a metaphor for units of energy. Each activity – i.e. showering, grocery shopping, sending emails – requires a given number of spoons, which can only be replenished through rest. The neologism is used to explain that activities cost more spoons from people with chronic illness or disability, who also often have less, as well as the careful planning they must do in order to effectively ration and replenish their energy reserves and how this differs from typical conceptions of energy expenditure, fatigue and rest.

● ● “Death panel” is a political term that originated during the 2009 debate about federal health care legislation to cover the uninsured in the United States.

A conversation with Daniel Koretz: a Professor who practiced inclusion.

Melanie Bates*

This summer I was diagnosed with Stargardt's Disease, which is an inherited eye condition that affects my central vision. The symptoms started kicking in as soon as I started my master's program at Harvard Graduate School of Education. The severity and the progression of the symptoms vary from person to person, but many people with Stargardt's have trouble with reading, driving, and recognizing others' faces. People with the disease might have dark or pixelated spots in the center of their vision. For me, I'm starting to notice pixelated spots depending on the lighting that I am in. Bright light is also very bothersome to people with Stargardt and some wear sunglasses to dim down the brightness of screens or natural light. Recently, I've found bright light reflecting from screens extremely bothersome, which has led me to dim the brightness on my phone and laptop. Stargardt's progression rate is unpredictable. Doctors and researchers are not exactly sure about what causes some people's condition to progress more quickly than others. Currently, there isn't a treatment for the disease, but there are a few things that may prevent quicker progression—avoiding vitamin A, avoiding excessive exposure to sunlight, and avoiding smoking, including second hand smoking.

* The name is a pseudonym, as the author wishes to remain anonymous.

● Kibbutz schooling emphasizes tightly knit peer groups and support from adults in the community. Teachers work with students to foster collaboration and cooperation rather than competition.

I have been learning to cope and navigate my way through life, primarily graduate school, with my recent diagnosis. Although my peers and professors have been kind and helpful, one professor comes to mind that has gone out of his way to accommodate not only my needs, but the needs of all of his students throughout his career.

Dr. Daniel Koretz described the beginning of his career as "accidental," particularly the start of his career as a special education teacher, but I personally think that he was destined to have taken the career path that he did. Koretz was working on a teaching team as an assistant to students that had emotional and behavioral conditions. He showed tremendous support and heart for his students. After a teaching position opened, he was offered the opportunity to become a special education teacher. As a special education teacher in a junior high school outside of Portland, Oregon, he was better able to meet the needs of his students by designing a program based on Kibbutz schooling ● in Israel. The program proved to be effective, driving Koretz to apply to Ph.D. programs so he could learn more about early intervention programs. He eventually earned his doctorate degree in Developmental Psychology from Cornell University. Koretz spent several years working at the Congressional Budget Office and RAND before entering academia.

Koretz began his position at HGSE in 2001. He taught S-11, Understanding Today's Educational Testing, which I enrolled in during the Fall semester of 2018. Despite the complex and rigorous nature of the course, it was the only class that I, along with other students, have felt truly accommodated in. I may have not approached Koretz if it wasn't for the anecdote that he shared with the class in the beginning of the year as he was discussing the topic of accommodation vs. modification in today's testing world. In his first class during the Spring of 2002, one of his students, let's call her Lisa, had a congenital eye condition making it difficult for her to see when there's bright light and fine detail. At that time, HGSE did not have a well-developed system to provide accommodations for students with disabilities, which often meant Lisa was not accommodated properly in her classes. However, Lisa didn't let that stand in her way. She voiced her concerns and demanded that proper accommodations be given to her. Koretz helped in the accommodation process by giving his lectures in a dimly lit room so that bright light wouldn't get in the way of her learning. He also printed out his slides (one slide per page) before every class so that she was able to see fine detail. Koretz shared that Lisa was a solid A student.

I approached Koretz after the third class and disclosed my condition. In my experience, most professors need to be reminded more than once, but not Koretz. By the next class, and for every class after that, full-sized slides were printed for me and they were in color! My exams were given to me in larger font as well.

For some, this might not seem like a big deal, but for me, it made a big difference. For me, it meant that someone cared about my learning and experience. It meant that I was acknowledged and that my disability wasn't seen as an impediment to my intelligence, but that Koretz believed in my ability to learn and understand the content.

Koretz's support didn't stop in the classroom, however. For months, I have been struggling to receive proper documentation from the Mass Eye & Ear so that I'm able to receive documented accommodations at HGSE. I told Koretz about this and he made one phone call to Access and Disability Services. I'm not entirely sure what happened during the phone call, but within a span of an hour, my accommodations were documented and sent out to all of my professors.

Dr. Daniel Koretz will be retiring from HGSE in June 2019 after 18 years of service. Through his advocacy and support for all his student, he has shown that small actions can make a huge difference in the lives of others. He will be dearly missed by the entire HGSE community.

Teaching Disability in a Medieval History Course

Valerie Piro

Valerie is a PhD student at Princeton University, where she studies early medieval history. Her research interests include the study of disability, poverty, and Christianity. Valerie has used a wheelchair since January 2008, but only became aware of disability as a historical subject during her senior year of college in 2013. Since then, she has written about disability, both within an academic context, and with regard to higher education administration. Her work has been featured in Inside Higher Ed and The New York Times. Her essay argues for the importance of including disability history in survey courses about the Middle Ages.

In the first semester of my History doctoral program, I was given an assignment to create an undergraduate course syllabus for the history of the medieval Mediterranean. This meant that I had to craft a reading list that would get across all the necessary points that a beginner student of medieval history should know, but would also be engaging enough that it could be appealing even to a student who (inevitably and begrudgingly) would take my class solely to fulfill a course requirement. This course would, if I had any say in it, count as a "general education" course.

The course was structured into fourteen weeks' worth of reading. I broke the course into two halves: the first seven weeks were an overview of the history of the Byzantine Empire, which would serve as a proxy for the medieval Mediterranean; and the final seven weeks were a deep dive into different thematic approaches. There are subjects that one cannot ignore when teaching the history of the medieval Mediterranean. I have to include Constantine's move of the Roman capital from Rome to Constantinople, iconoclasm, the eleventh-century crisis, the Crusades (especially the Fourth Crusade), the eventual fall of Constantinople, and many major events in between. These were introduced in the first half of the course.

I dedicated the second half of the course to the following themes: Languages in the Mediterranean, Education and Knowledge, Gender, Disability, the Urban and the Rural, Religion, and the Mediterranean World. This latter half of the course's themes could be switched around in later years, depending on interest. If students wish to learn more about race or poverty (or even sports culture) in Byzantium, then that could be arranged. The goal is to ensure that students are getting an overview of medieval history, and then to reinforce that material through specific thematic approaches. These thematic approaches ought to be those through which students can latch onto a modern equivalent, and thereby find the material a bit more accessible. I treated my hypothetical course as one geared towards those who had never taken a history course before, in addition to those who were at least vaguely interested in what the Middle Ages had to offer.

You may have noticed that I have a whole week dedicated to disability. After taking at least a dozen pre-modern history courses at both the undergraduate and graduate levels, I can assert confidently that if a professor has their own research interests, then they will find their way into a syllabus. It does not matter whether the course is a general survey or a more specific seminar. If a professor wants a subject to be taught, then it will be taught.

Disability is one of my many research interests, and thus it made sense that a week centered on disability studies and medieval history was warranted. Some might argue that I should stick with a broad overview, and that more particular research interests ought to be relegated to a smaller seminar setting if they deviate too much from this overview. While it is always tempting to craft a course based solely on disability, I find that a disability studies course has the potential to attract only the audience that already has an interest in the subject. A course on disability in the Middle Ages might attract students already interested in history or medieval studies, in addition to those curious about disability. In either case, I am supplementing either medieval history or disability theory. But why not teach both simultaneously? I want to broaden my audience to include students who would take a general education history survey course.

It must also be noted that disability does not deviate from the larger narrative of medieval history. Much like gender and class, disability is part of the medieval world. We cannot understand how medieval society was structured or operated if we focus only on the monarchs and the ruling elite. Through each thematic approach, my future students may uncover a different facet of medieval society that will enhance their learning as a whole.

Because the field of medieval disability studies is rapidly growing, there are many readings I could have chosen for my syllabus. I decided to start with the introduction to Irina Metzler's Disability in Medieval Europe. She summarizes a number of modern preconceptions about disability in the middle ages, some of which my future students may already hold. We shall progress from there to a couple of selections from scholars who have done research on disability in the Byzantine Empire and the medieval Islamic world. Finally, we have Catherine Kudlick's article, "Disability History: Why We Need Another 'Other.'" The corresponding lectures will focus on disability theory, its origins in the disability rights movements of the 1960s and 1970s, and how we can use this theory to study disability in the middle ages.

Part of this subject's inclusion in my syllabus is personal.

Although I spent the entirety of college being disabled, I knew nothing of disability studies. I did not think disability was a serious topic of study, but instead a modern civil rights issue.

My college did not offer a disability studies minor field, and I never thought to search for a disability studies course (I later discovered that my university offered three courses, one of which I would take years later as a graduate student). It was not until my senior year of college that I stumbled upon Metzler's work on medieval disability, but by then I already had chosen a research topic for my senior thesis. A dissertation on early medieval perceptions of disability would have to wait until graduate school.

An advisor warned me not to let my research become "me-search." I understood his concern. No one wants to be academically typecast as "the person who is disabled and talks only about disability." It could be a disadvantage on the job market, and more importantly, it misrepresents what I can offer as a scholar.

My research interests involve the history of early Christianity, legal access for the poor in the pre-modern period, and the history of sport. Perhaps my interest in disability studies and personal experience with disability has allowed me to see applicable modern models of disability in more historical sources than would someone who does not possess this background. If that is the case, then I would be remiss not to share this approach to history with my students.

I have never found disability to be a distraction from the study of the middle ages. Rather, I find that it broadens how we think about the past and reflect upon the present.

In my own research, I have found that individuals from the fourth century onwards have tried to define disability and found it difficult, much as we do today. In my readings, and in the readings I intend to assign to future students, disability appears more nuanced and complicated than one would have imagined. Indeed, most topics can overlap with disability and impairment.

It is true that, as with many subjects in the Middle Ages, we do not have enough sources written by the population about which we want to study. We face similar hurdles when teaching women's history and the history of peasants in this period. Nevertheless, we may construct a picture from the sources that have survived: saints' lives, legal codes that discuss acquired physical impairment and qualifications for mental incapacity, chronicles, and narrative sources. We have to dig a little deeper, but the sources are there, and the stories they tell are always worth examining. And you bet my future students will be given these primary sources along with the introductory excerpts mentioned earlier.

It is important to note that this course has never been taught, and that my teaching plans are aspirational at this time. As a result, I cannot tell you whether my hypothetical students have engaged with this material, or simply pretended to do the reading. But if given the chance to bring a course to life, this week's worth of material is going to make the cut in my final syllabus, even if I have to squeeze it into one lecture (I understand I may not have the luxury of a fourteen-week syllabus depending on where I teach).

I encourage all those who teach the Middle Ages to dedicate some part of their syllabus to medieval perceptions of disability, especially if they had planned to teach other aspects of social history. We cannot continue to ignore an entire population's past and simply relegate the study of it to a specialized seminar.

The study of the Middle Ages is expanding to demonstrate how diverse the medieval world in fact was. The area surrounding the Mediterranean was one of various languages, literatures, religions, identities, and abilities. We are doing our future students a disservice if we do not highlight as much of this as possible.

Accommodations in Higher Education: A Student Perspective on Invisible Disabilities

Lindsay Burris and Haya Bacharouch

Lindsay is an Ed.M. student at the Harvard Graduate School of Education participating in the Mind, Brain, and Education program. Before enrolling in graduate school, Lindsay spent seven years as an elementary special education teacher. In this role, she developed a passion for advocacy and celebrating neurodiversity. As elementary and secondary schools across the nation continue to wrestle with ways to better support students with disabilities, she hopes that higher education can lead the nation in empathetic conversation and inclusive practices.

Haya Bacharouch is a master's candidate at the Harvard Graduate School of Education. She is receiving a degree in Education Policy and Management. Prior to entering her program at HGSE, she was a teacher. Being in the classroom, she recognizes the need for an inclusive education, and adopted the UDL framework in her classroom to better meet the needs of all students. She is passionate about being part of the IHED organization because she believes that inclusive education for all students, particularly students in higher education institutions, is critical to helping all students succeed and learn.

In teacher preparation programs across the United States, pre-service educators are taught the importance of inclusive education and disability rights. In law-abiding districts, providing appropriate accommodations to students with different learning needs is considered a crucial responsibility – not simply an optional action. Knowing that inclusive mindsets and practices continue to progress in the nation's public-school districts, both authors were surprised to see variable responses to more invisible forms of disability in the higher education setting. In discussions with peers that access disability services, the authors heard that invisible forms of disability felt less accepted than those of a more visible nature. Respondents noted that their peers often get caught up in the normative way of doing things and forget about the beauty of diversity until there is an optical reminder.

These responses often stem from a lack of awareness and understanding. Feeling silenced by the stigma associated with needing medical or learning accommodations hinders many people with disabilities from sharing their story. The power of a story is that it transposes listeners into a new time and space - one where they can briefly situate themselves in the perspective of the storyteller.

In the initial phases of writing this piece, the authors discussed ways to raise awareness around this sensitive topic. They wanted to elevate student voice surrounding the need for and response to accommodations on college campuses. Narratives from current students felt like an ideal way to begin the conversation and help communities better understand the needs of those with invisible disabilities. In the sections that follow, you'll read anonymous* stories from four graduate students with disabilities. These stories were initially collected through an online survey where participants could elect to elaborate on their responses in a personal interview. We hope their stories spark increased understanding and lead to more respectful conversations surrounding accommodations in higher education.

Juno*

Juno has found it frustrating and disappointing to discuss her medical condition during her time as a graduate student. Juno's anxiety began in her transition to graduate school. She discussed that it was extremely challenging to receive accommodations. She was bounced around between three different people meaning that she had to tell her story not once, not twice, but three different times before she finally received proper accommodations for her medical condition. Juno reported that navigating Access and Disability Services has been easier than navigating her university's mental health department. For many students with anxiety, access to a supportive therapist that understands the demands of graduate school is integral for academic success.

After finally receiving the appropriate medical documentation for her diagnosis, Juno received accommodations for her classes. Her accommodations included extensions on deadlines because she has difficulty meeting overlapping due dates that usually result in compounding anxiety.

Throughout Juno's survey responses, she made it clear that her medical condition of anxiety is highly stigmatized making her feel uncomfortable disclosing to her peers that she has accommodations for anxiety. She writes, "…[anxiety] is misunderstood as something that everyone has to a certain extent. It's a very invisible mental health issue that is isolating in that respect."

Marcus*

Marcus is a current master's student with a diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) and dyslexia. He participated in special education programming until 9th-grade before transitioning to a 504-plan his junior year. He states that his current accommodations include having a class notetaker, using assistive technology to draft written documents, extended time on assignments and tests, and taking tests in a private location.

Marcus said that accessing disability services at the master's level has been a much more positive experience then what he experienced during his high school and undergraduate years. He felt like it was a constant battle to get appropriate accommodations when he was in high school, and navigating disability services during his undergraduate studies was a very public experience. He had to hand-deliver a disability services letter to each professor, and leaving the room to take assessments was a public affair. Consequently, the responses from peers were often negative, and he felt misunderstood. At the master's level, his confidentiality is better protected, and his professors respect his need for accommodations. "I really appreciate this level of respect," said Marcus, "because my professors normalize disability, respect my intellectual contributions to the learning environment, and give me the power to decide if and how I tell my classmates about my disability."

Leah*

As a current master's student, Leah accesses disability services for a chronic digestive disorder. Not being diagnosed until after completing her bachelor's degree, Leah navigated disability services for the first time when enrolling in graduate school. She noted that accessing these services was pretty easy, but it took a long time to gather all of the paperwork and put a plan in place. Her current accommodations include excused absences from class, extensions on assignments, and accessing a class notetaker. When asked to describe how these accommodations help, Leah said, "In addition to abdominal pain, excessive fatigue is also really common, so my accommodations make it easier for me to focus in class."

While most professors have responded positively to Leah's need for accommodations, she wishes that accommodations offered more autonomy. For example, the school opted to give Leah use of a notetaker rather than recording lectures because some professors dislike having their lectures videotaped. She went on to explain that notetakers can sometimes be difficult: "… it takes the university a really long time to hire notetakers. The quality of note-taking varies, too. When other people take notes for me, I have to rely on what they think is important. If professors are willing to record the lectures, then I get to decide what is important." Leah concluded her reflection by noting how much she appreciates professors that implement the UDL (Universal Design for Learning) approach because their classes are naturally accessible for all students.

This helps Leah to blend in; she doesn't need to ask for anything not available to other students.

Omar*

Omar is a current master's student and has had access to accommodations since his undergraduate career. Since Omar has already gone through four years of college with proper accommodations, he has been better able to manage and navigate his way through graduate school. Omar is diagnosed with a condition that affects his autonomic nervous system, which regulates the function of the body's internal organs, such as heart rate, blood pressure, digestion, and body temperature. Autonomic disorders can result in unstable blood pressure, dizziness, fainting, lightheadedness, and other symptoms that can hinder his attendance and ability to focus in class. Omar's current accommodations include flexibility with the attendance policy, as sometimes he may need to miss a part or the whole class depending on the symptoms during that specific time. Omar also has access to a note-taker for when he misses class.

Like other students, Omar has expressed that professors are highly responsive and accommodating. However, Omar discussed that although his classmates are friendly and supportive, there is a lack of understanding when it comes to his diagnosis. Omar revealed that most of his classmates assume that he has a cold or virus when he's not feeling well, and some suggest that he should go home to rest. Omar writes, "...it's hard to explain that I've chosen to be in class, that I won't make them sick, and that I'll only leave if I choose to, especially while trying to concentrate in class." Omar's narrative is similar to those of the students who responded to our survey and who we have talked to personally, which reminds us that it's important to be cognizant of the fact that not all disabilities are visible.

Our narratives only capture the experiences of a few students, yet numerous untold stories exist in colleges and universities across the nation. Despite this, the stories presented in this article show a common theme: invisible disabilities are often not believed, understood, and appropriately accommodated. Those with invisible disabilities are confronted with disbelief by their friends and colleagues who cannot visibly see the impairment, and associated stigmas make it difficult for people living with invisible disabilities to feel accepted in professional settings. Thankfully, professors and students can take intentional steps to improve the community culture in higher education:

Students:

1. We've all done this at some point, but it's important to not assume what your peers are going through. Reach out and have a conversation. Understand the nature of the disability and dispel the myths that exist.
2. Understand that accommodations are not "unfair advantages." Instead, they help students with disabilities fairly access the learning environment. If you find out that one of your peers uses accommodations, exercise sensitivity.
3. If a classmate or friend tells you about their invisible disability, refrain from telling others.

Professors:

1. Start off your semester by letting all students know that they can talk to you about their specific needs and the best way to accommodate them. This can be done through a survey handed out during the first week of class.
2. Embrace Universal Design for Learning.
3. Students may not always approach you. If this is the case, approach the student and ask whether or not the adjustments are sufficient, and let the student know that you're available for support.

Many people carry an invisible disability that heavily impacts their life on a daily basis. Some examples include chronic pain, mental illness, or autoimmune diseases. It's time that we have more open and honest conversations around the topic of invisible disabilities. It's time for those in higher education to lead the nation in disability awareness and acceptance.

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*Pseudonyms were used to ensure anonymity.

Embracing Blindness

Miso Kwak

Miso is a student at the Harvard Graduate School of Education. She will be graduating in May 2019 with a Master of Education (Ed.M) in Education Policy and Management. Motivated by her personal experience of growing up as a 1.5 generation Korean-American ●, blind person, she dreams of a world in which all students, especially those with disabilities and/or those who come from low socioeconomic backgrounds can reach their maximum potential through equitable and inclusive education. Through this essay, “Embracing Blindness,” Miso offers a critique on the narrative of “overcoming” disability. More importantly, she challenges her readers to view disability as an identity to be embraced by sharing her own journey of embracing her blindness.

● I identify as a 1.5 generation Korean-American, because I immigrated to the U.S. in my early adolescence, and therefore have cultural and linguistic understanding of both Korea and the U.S.

*The school name has been changed to ensure anonymity.

When the New England autumn began to turn into winter and as deadlines for various final projects approached, I received an invitation from an elementary school principal inviting me to be a guest speaker for the school's "Ability Awareness Day." Although I was excited about the opportunity, I was also a bit troubled by the title of the event. I thought to myself, "Why do you just not call it "Disability Awareness Day"?' My concern only grew when I read the actual invitation, a part of which read, "The purpose of Ability Awareness Day is to raise the consciousness of Hilltop* students in a variety of ways. We believe the day provides students with meaningful opportunities to interact with and be in the presence of other children and adults who have overcome particular challenges." It was clear that the principal meant well, and I even admired her for inviting people with disabilities to the event. What bothered me was the notion that people "overcome" their "particular challenges," which I interpreted as disabilities in this context.

I was tempted to decline the principal's invitation. The title of the event, "Ability Awareness Day," communicated the school's hesitancy to actually name disability for what it is. Framing people with disabilities through the overcoming narrative seemed to further the idea that disability is something that people have to minimize and triumph over. However, I accepted the invitation as a form of resistance.

> **According to the dictionary, some of the definitions for the word "overcome" include "to surmount", "to conquer", and "to defeat." Based on these definitions, I have not and do not foresee overcoming my blindness. There is nothing to surmount, conquer, or defeat because blindness in itself is not an obstacle.**

Rather, the ways in which our surroundings are designed (e.g., web pages that are not compatible with screen reader softwares), as well as societal misunderstanding and fear toward blind people (e.g., doubting blind people's capability to dress fashionably) are the obstacles through which I have to navigate. In my view, disability is an identity that one chooses to embrace, which can be defined as "accepting or supporting an idea willingly and enthusiastically."

Although I have been blind for as long as I can remember, the journey of embracing my blindness began when I was a sophomore in high school. I was on the turf at a marching band rehearsal. The rehearsals were getting more and more intense as the championship of the season grew closer.

"HALT," the drum major yelled. "SET!" We all put our horns down, turned around, and ran back to the starting position.

"She's out of the line. Move her back," a freshman girl whispered, but it came off more as an order than a whisper. I instinctively knew she was talking to Stacy, who was guiding me during this particular rehearsal, and was talking about me. To me, it was a breaking point of the feelings about my blindness I had been bottling up in the months that led up to this moment.

I was raised by parents, who, for the most part, fit the Asian tiger parents stereotype. My blindness did not stop them from having high expectations for me. They also did not hesitate from engaging in a strict parenting style, especially in regard to my academic performance and self-discipline in extracurricular activities such as practicing the piano and having me take the responsibility to wash my swimsuit by hand after every single swim practice. Although I had experienced prejudice and discrimination, I was always taught to be strong, sociable, and hardworking. The underlying message seemed to be that If I could prove to others that I can perform as well as or better than my sighted peers, I would be able to succeed in this world. Subscribing to these beliefs, I put myself through whatever I wanted to do, one of which was joining the marching band as soon as I entered high school. My teachers thought it would be impossible for a nearly totally blind person to march, but I persuaded them to give me at least a chance. We initially tried using two ropes to connect me with the person directly in front of me and the person directly behind me. This strategy worked temporarily but it made complex and precise movements difficult. After more research and somewhat by coincidence, we learned that the Ohio State School for the Blind had a marching band that was composed of blind marchers and sighted guiders. The band had been selected to march in the 2010 Rose Parade ●● and used my high school stadium as a rehearsal site. My band director and I adopted their strategy. Someone would stand by my left shoulder and make sure that I march in line with the rest of the band. This was just another thing I convinced sighted people that I was capable of doing, and I felt great about it.

By the time I became a sophomore, however, I felt my attitude and thought processes shift. With geometry, chemistry, honors English, and Advanced Placement European History on my schedule, I could not help but notice how much more time I had to put into my studies compared to my sighted friends. I found myself often thinking that if I could just see what my math teacher was drawing on the board or examine the map of Europe, my life would be so much easier and more efficient. This line of thinking bothered me as much as the fact that I needed more time to keep up with my assignments. I was worried that my parents would notice these thoughts. I felt that it was so much the opposite of how they taught me to be. I was afraid that if they found out about my feelings, they might feel betrayed, so I them to myself. However, at that moment, when a freshman criticized my guider and me for being out of the line, they came out faster than I could manage. Before I knew it, tears filled my eyes. I was utterly embarrassed that I was crying in front of approximately a hundred of my peers, so I wiped my eyes and got back into the rehearsal.

After the rehearsal, my band director and I sat down on a planter near the band room. I told him what had happened during the rehearsal, that I sometimes hated being blind, and hated even more that I had those feelings. After listening to me, he responded, “I think it’s okay sometimes to hate that you are blind. I sometimes hate that I am fat.” I remember laughing out loud at such an unexpected response. But, it was then that I realized that someone I looked up to who did not seem to have any problems in his life also had something he did not like about himself. I also began to understand that blindness is a part of who I am, rather than a problem I can solve merely by working hard.

Knowing that it was okay to hate my blindness once in a while brought me great relief. However, the struggle to make sense of my blindness continued throughout the rest of high school. I constantly tried to fit in and thrive both academically and socially.

A few years later, I enrolled in a course titled “History of Deaf Communities in America” during my sophomore year of college. On the first day of the course, I sat in front of the classroom, excited and nervous.

It was the first time I had a professor with a disability and the first time I was interacting with a totally deaf person. When the 1 hour and 15-minute long lecture was over, I left the classroom wishing I was a Deaf person, just like my professor.

I could not believe I felt this way, but I was fully convinced that my professor took great pride in his deafness. I also wanted to feel that.

This experience prompted me to reflect more deeply on how I think about my blindness. Up to that point, I had lived my life trying to always compensate for what I do not have and perhaps overcome my blindness with my work ethic. Deep down, however, I knew that I could not change my blindness. I also knew that the mindset of always trying to prove myself to others was not good for my mental health. I began to wonder if I could present my blindness in a way that would communicate an authentic self-confidence rather than a desperate desire to cover it by conforming and fitting into the majority.

Since that class, I have been consciously choosing to identify myself as a blind, disabled person. Doing so has allowed me to talk about the challenges that come with being blind more comfortably. It has also allowed me to think of my disability as an asset and a part of my identity that shapes my aspirations and values.

I still have and will continue to have days on which I hate being blind, so I have overcome my blindness in neither medical terms nor psychological terms. Rather, I am learning to embrace both the good and the ugly aspects of my blindness.

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In mid-December, after all of the final projects had been completed, I visited Hilltop Elementary School for the "Ability Awareness Day." Within the few minutes, any feelings of anger I had harbored toward the way in which the school's administration framed disability through the overcoming narrative melted away. The young students were eager to learn about braille and asked insightful questions such as "If your cane can only tell you what is in front of you on the ground, how can you avoid things like tree branches?" and "Why do some blind people have a guide dog, and you have a cane?" Their excitement toward braille and such questions showed me these elementary school students' genuine acceptance of who I am as a blind person. More importantly, I was delighted to find that the students had an open mind to learning about how I navigate the world, rather than telling me how I should.

●● The Rose Parade is an annual parade that takes place on New Year's Day in Pasadena, CA, along the 5.5-mile long route. The parade attracts thousands of people to the event and is broadcasted nationally in the United States.

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THAT'S WHAT MAKES YOU BEAUTIFUL: PRIVILEGE, ABLEISM AND DESIRE | Allan Hennessy

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"BUT WHEN YOU'RE SICK, YOU GO TO THE DOCTOR" | Zina G. Noel

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