

• DISABILITY

• DISCLOSED

A publication produced by
the International Higher
Education and Disability
organization at Harvard
Graduate School of
Education.

IHED 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.

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Thank you to Inés Benítez Gómez for the beautiful and creative design of this publication for the second year in a row. Inés has worked tirelessly to produce beautiful results for our now completely digital issue, and has been flexible with our evolving plans. We are so appreciative of her talents.

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Note from the Editor:

05/2020

Like any community, the disability community at large has faced many uphill battles in the struggle for justice. Today, we continue to bear witness to the waging of some lives as more valuable than others. In the wake of COVID-19 and worldwide shortages of life-saving medical equipment, there has been a noticeable uptick in dangerous rhetoric about disabled lives. There have been not only implications, but unapologetic statements, that the death of a person who is elderly, who is immunocompromised, who is already living with a disability, is merely collateral damage in this unprecedented global health crisis. Those of us who are listening have begun to ask questions, and to make demands. Where are our voices? Who are our advocates? What makes one person less deserving of a respirator than another?

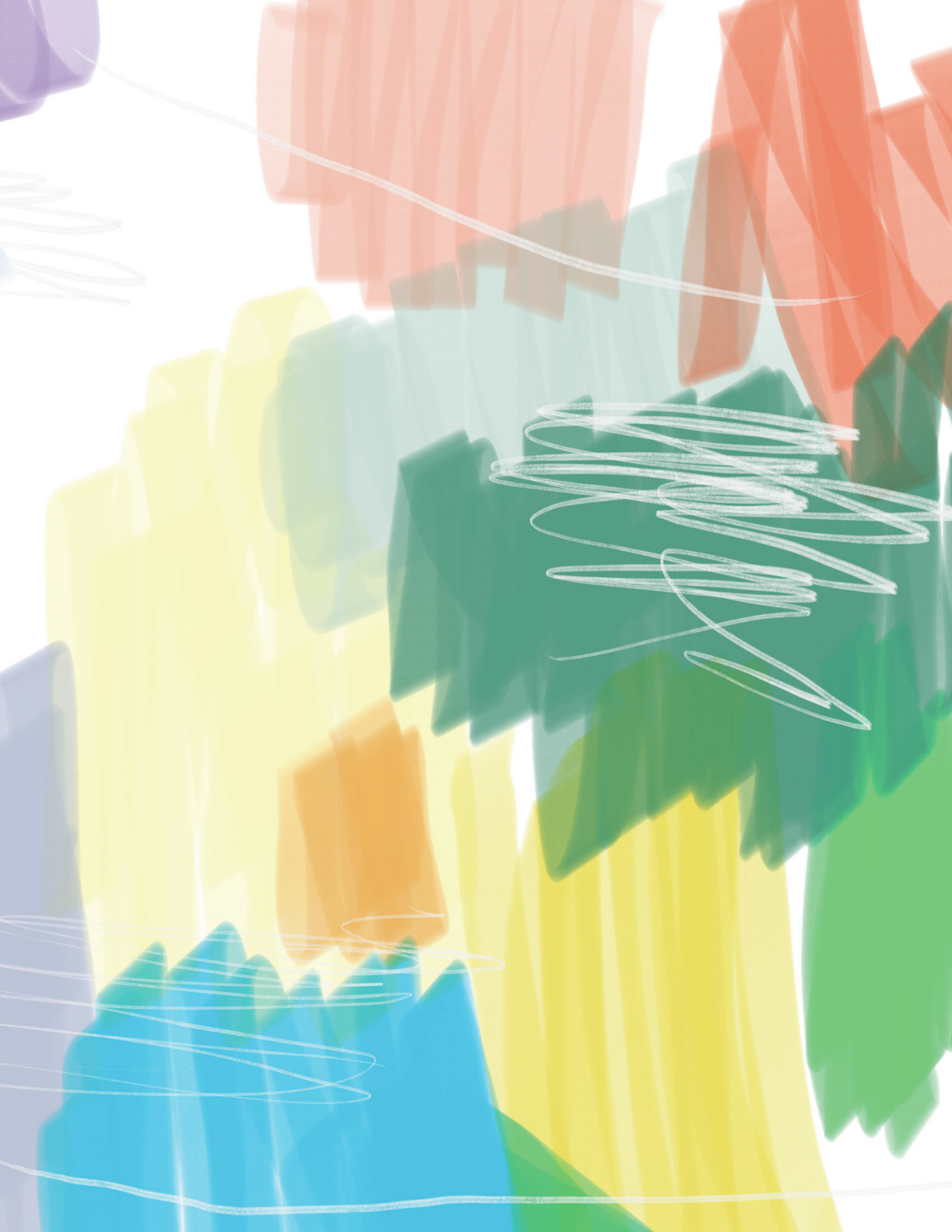
This issue of Disability Disclosed is the second ever issue of the journal, and IHED members had envisioned a very different outcome for the project when we began meeting as a group in the fall of 2019. We envisioned many more meetings and celebrations together, a hard copy of this issue to be circulated through university libraries, and a launch event with friends in the spring. I know that many of our group members envisioned having more time, more energy, and more resources to devote to submitting a piece. I had originally drafted a very different editor's note than the one I am writing now. Instead, as pieces began to be received and edited, undergraduate students at Harvard were instructed to leave their on-campus homes, courses at HGSE and across campus began online instruction, and all campus buildings effectively closed for the remainder of the semester. Our time and energy, especially the time and energy of disabled students, had to focus elsewhere. It has truly been, as we have heard many times, an unprecedented experience.

Despite all of this, I am thrilled to see that our project has been able to transition to a solely digital platform, and I hope that in this format it can become accessible to more readers. I feel very proud of this collaborative work which has, during such dark and uncertain times for our community, offered stories of resilience, power, and identity from students across Harvard campuses. Disability Disclosed began as a project seeking to amplify disabled voices at Harvard, and I believe that it came not a moment too soon. In the aftermath of the COVID pandemic, it is crucial that we not cast aside disabled voices, but listen, learn, and advocate fiercely. To quote our founders, disability is a part of the human experience, and an invaluable element of human diversity. We offer our stories in collective mourning and celebration for the lives lost to COVID-19, and we continue our work in hopeful pursuit of a brighter future.

Libby Federici

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Sarika Chawla

On Womanhood

My brother says that everyone knows who I am. and

You're The Girl in the Wheelchair,

he says,

Everyone knows who you are,

and my mom adds,

Yeah, it's like an identifier:

the boy with a birthmark on his cheek,

and my brother,

the girl with long blonde hair,

and all of us,

The Girl in the Wheelchair.

But what if I don't want to be

The Girl in the Wheelchair?

What if I was the girl who

zooms around town in a hot pink

rolling chair? That'd be pretty

neat,

wouldn't it?

But it would still be

The man with an eyepatch

and

The woman with a mustache

The Girl in the Wheelchair.

Everyone knows who you are.

Tell me, how can you

claim

to know who I am

Speedy Gonzalez! Hahaha!

by defining my identity

You should get a horn to

warn

people you're coming!

with a chair

You're gonna get a speeding ticket!

with wheels

You're so lucky you get to sit all day.

that moves.

I feel so bad for you.

You're The Girl in the Wheelchair.

What if I don't want to be The Girl in the Wheelchair?

What if I want to be the girl with two piercings



in her right ear and a third

on the way but only

one

in her left ear because the second one got infected and then she decided she liked the asymmetry.

What if I want to be the girl with

cool leggings and

colorful fleece hoodies zipped up

over her mouth because she's always

cold and

the girl with an untameable mane of

poofy tangled

roots from the jungles of India.

What if I want to be the girl who browses

baby name sites

for fun,

the girl whose first love was Spanish,

the girl who turned out to be a sweet,

loyal

Hufflepuff

despite insisting

she was a strong and brave and fearless

Gryffindor.

What if I'm the girl who shops in the Disney store

for prom shoes because

she has the soul of a child and her favorite

princess

is Belle and she loves Beauty and the Beast because she is

the Beast and also because

she has feet a size too small

and a heart ten sizes too big.

What if I want to be a woman?

What if I were to tell you that I believe

I am a princess

and I am a woman

Eres una reina.

and I am a fucking queen.

all over her body.

I am a queen and my first love was Spanish.

I want to be

Soy una reina.

la mujer con un bigote.

I want to be a woman.

Eres mi reina.

Quiero ser una mujer.

Eres mi

I want to be the woman who gives good head.

I want to be *una*

Ay mamita, dame más

mujer.

I want to be the woman who brings you

Eres—

to your knees with her writing, who

I want to be—

can say “I love you” in all the languages

I just want to be.

of the world,

I want to fall asleep at night

who cheats on Spanish, the woman who

Good night, Hufflepuff.

speaks

and feel beautiful.

French between your legs,

Te amo.

Eres una perra en la cama

Te amo.

the woman who’s mind-blowing

Chiquita, niñita,

in the bedroom.

muchacha linda,

mujer bonita,

I want to be the woman who gives hugs

bella reina,

for hours on end because she’s soft

diosa hermosa,

and warm

mi querida chica con la silla de ruedas,

from those few extra pounds on her stomach

my dear girl with the wheelchair,

because after Spanish, her second love

te amo.

was food, and I want to be the

woman



who entangles continents in the Indian jungles

growing

What working in a research lab taught me about perceptions of disability—and how to change them

Transcribed from a TEDx talk given at Concord–Carlisle High School in Concord, MA on March 3, 2019

When I was eight, I asked my best friend if I could join a club she'd created. She told me, "No way! You're in a wheelchair. You can't do anything!"

I remember crying in my parents' arms soon after and questioning if my friend was right. Yet, I also recall them telling me I could do whatever I put my mind to. As I grew older, I tried to remind myself of my parents' words and never let my disability define me.

But I would falter along the way.

When I was thirteen, a doctor told me that university researchers wanted to study my congenital tumor, which had damaged my spinal cord and left me with paraplegia. For the first time, I realized that scientists could learn from my condition to help remedy others; I soon made it my passion to do the same so maybe one day, I could develop a cure. Scientific research would revolutionize medical treatment, and I was driven to make my own contribution.

So, as a junior, I emailed nearby professors about possible internships, and eventually, Dr. H. Robert Horvitz, from MIT, offered me one. That summer, I would study genes implicated in ALS and frontotemporal dementia, or FTD, by performing experiments on their counterparts in microscopic nematode worms.

Armed with pipettes and a worm pick, I entered the lab ready to advance disease treatments. But after weeks of gene cloning and DNA purification, I was no closer to accomplishing my goal. Frustrated, I asked my lab members what potential implications my simple work had for curing ALS and FTD. As I tried to make sense of my role in the lab, a postdoc named Kirk said something that struck me. He said: "I don't like purely disease-driven mindsets. As biologists, our goal is to understand life. It's great if our work leads to treatments, but if all we focus on is curing a specific disease, we might miss out on other important observations or findings."

Slowly, I realized that maybe I, too, had fallen into the trap of having a solely disease-driven mindset; in more ways than one, my tumor had paralyzed me and my thinking.

I've learned that my initial outlook was just one, narrow lens with which to view research, one of many. Ultimately, research adds to the existing field of scientific knowledge and helps us better comprehend complex phenomena in today's world. Only with a detailed understanding of the causes of disease can we engineer solutions to scientific problems or enhance current solutions, whether those be medical, environmental, or something else. I've come to change my mindset to one that lets me approach research as a tool for exploration and discovery. While I still hope to one day develop a treatment for paraplegia, that isn't my only focus.



It shouldn't be yours either.

I shouldn't be the only one focusing on changing my mindset and breaking out of the narrow, disability-driven view I once held; abled people need to readjust their own focus as well

because for too long, society has harbored a harmful view of people with disabilities. Many abled people subject themselves to a different type of disease-driven mindset, reducing those with disabilities to nothing more than their perceived disease. This hurtful mentality often takes two different directions, which I'd like to share with two different stories—one about kids and one about adults.

In eighth grade, after my English teacher gave back a project, my classmate told me that I only got good grades because teachers felt bad that I used a wheelchair. But we had classes together for the next few years and, over time, he saw me ask questions, contribute to discussions, and dedicate myself to my work. Eventually, these observations complicated his oversimplified judgment of who I was, and he came to realize that I did well in school because I worked hard and enjoyed learning.

My classmate initially attributed my success to a wheelchair, and this is one form the disease-driven mindset often takes. The other form is the idea that my wheelchair prevents me from fulfilling the most basic needs.

Recently, I was at a get-together and a neighbor asked my mom, "When Sarika goes to college, are you going to go live with and take care of her?" She assumed that my wheelchair prevented me from ever being independent, which reveals a mindset that those with disabilities can't do what abled people can. My mom explained that I can, in fact, live independently and take care of myself, and that I'm even learning to drive soon. Our neighbor was surprised that I could live my life like most other people, and it opened her eyes to realizing that my disability doesn't actually limit me.

This got me thinking: if my eighth grade classmate and my neighbor could change their mindsets, can we get others to change theirs too? A disease-driven mindset is often subconscious, something we don't realize we have. It's critical that people are more informed about this and treat those with disabilities with the dignity they deserve. We need to create a positive, more inclusive way of thinking.

Let's work together to disable the disease-driven mindset.

It's important to realize that the world is unfair, but moving forward, I ask of you: for whom is it unfair?

We need to reevaluate how we speak to and about those with disabilities. Often, we have perceptions without truly getting to know the person. I'm asking you to have the moral courage to get to know someone who is differently abled and understand them better. There is more complexity to them. They are more than just a disability. We need to think about everything that makes up the identities of those different from us instead of jumping to conclusions based on limited information.

At eight, I promised not to let others' perceptions of my disability define me; at one point, my own perceptions did just that. But different lenses exist through which I can view myself. Just like developing cures is one part of research, my disability is one part of me. It's not the only part of me.

And on that note, I imagine there's more to all of you than meets the eye. So, I want to leave you thinking more about perception and mindset. I've changed mine.

Why can't you?



Chronic illness is not widely viewed as disability. This needs to change

You would be forgiven for thinking that in the US people with disabilities have full inclusion and equal participation in society. After all, the Americans with Disabilities Act (ADA) protect individuals with disability from discrimination. It requires that workplaces and educational institutions provide reasonable accommodations for people with disabilities to work and study effectively. Specifically, the ADA defines disability as “any physical or mental condition that substantially limits a major life activity.” Although people with chronic illness –that is constant or occurring repeatedly over a long period of time - are included in this definition, popular imagination tends to think of disability as mobility, sensory, and learning impairments. Not only is chronic illness the leading cause of disability in the US but also people are increasingly being hit with chronic illness earlier in life than in the past. Yet, as there is little understanding in workplaces and educational institutions about the nature of chronic illness and the barriers it creates, access to education and employment for the chronically ill remains far from equal.

Firstly, the similarities between chronic illness and impairment are not well understood. Impairment is what is absent or different in a person’s body structure or function. Mobility and sensory disabilities, for example, have localized impairments in the limbs and senses. The impairments associated with chronic illness tend to be systemic, affecting the whole person. Of the hundreds of chronic illnesses, the most common impairments relate to chronic pain and fatigue, resulting in decreased stamina for everyday activities like walking, standing, concentrating, and learning. People with chronic illness often need to plan their energy expenditure so that they can carry out their daily self-care and household tasks, as well as their work or other goal oriented activity. So while loss of limb or eyesight is clearly impairment, understanding the impairments caused by chronic illness is complex and subtle.

Secondly, chronic illness is commonly seen as ‘sickness’ rather than ‘disability’. As most people have been sick

at some point or another, experiencing significantly milder symptoms to the chronically ill (i.e. tiredness, pain, dizziness and headaches), the experiences of those with chronic illness can be trivialized. All too often, people with chronic illnesses like Multiple Sclerosis, Arthritis or Endometriosis are seen as exaggerating common problems, and perceived as lazy, ineffective, and an unnecessary burden. A simple example is that most people don’t know the difference between the overwhelming weakness and inability to function caused by medically-defined fatigue and normal, even extreme, tiredness. In truth, the experience of the chronically ill cannot be fully understood or imagined by healthy people. That is why it is time to educate our institutions and ourselves.

Thirdly, most chronic illnesses are invisible, which can lead to misunderstandings. We usually can’t tell from someone’s appearance that they suffer from chronic pain, fatigue, or mental health conditions that may limit their life activities. As a result, people with invisible chronic illnesses are often accused of faking their impairments and continually face trying to prove that their impairments are real. Women and people of color with invisible disabilities are further disadvantaged. To illustrate this, a 2016 study on the workplace supports people with invisible disabilities want versus what they get found that women have “satisfaction gaps” that are three-fold larger than men.

Lastly, chronic illness is multi-causal, unpredictable and unstable. While mobility, sensory and learning impairments tend to be stable, chronic illness fluctuates in severity on a day-to-day basis. There are days when an individual can function normally, days when they cannot, and many days with limited functionality; and bad days can’t be predicted. In view of the day-to-day fluctuations common in chronic illness, and unlike people whose disabilities require one-off accommodations such as building accessibility or adaptive equipment, the chronically ill tend to require sustained and flexible support.

than those with three or four conditions. Tracing impairments attributable to the various conditions in the mix becomes all the more difficult. This makes it challenging for chronic illness sufferers to justify their needs in work and educational settings.

The impact of chronic illness on individuals and society is considerable. The unpredictability of the conditions makes it difficult for the chronically ill to maintain regular, 9-5 jobs. They may end up missing work on bad days, unable to cover their work in the allotted time or cover everything poorly. Often, those with multiple chronic illnesses are forced to drop out of work altogether. This has consequences for the economy. The total cost in 2016 for treatment for chronic conditions was 1.1 trillion – amounting to 5.8% of US GDP. When lost productivity is included, the total costs of chronic conditions reaches \$3.7 trillion, equivalent to 19.6% of US GDP – that is a staggering one-fifth of GDP.

Combining chronic illness with full-time study is also a challenge. Students with chronic illness are often forced to miss classes, struggle with coursework, and maintaining good grades becomes all the more difficult; as well as facing periods of absences lasting months or years, which can take a major emotional and financial toll. Many are forced to drop out of education altogether. A 2011 study found that young adults with childhood-onset chronic conditions are half as likely to graduate from college than young adults without chronic illness.

The personal impact of chronic illness is also devastating. People with chronic illness often start missing social engagements and may become socially isolated over time. All too often, chronic illness can spiral out of control. A 2018 study found that 35% of those with a chronic condition reported having problems paying medical bills over the previous 12 months, compared to 27% of the overall public. And unemployment makes it more difficult to access medical treatment due to reduced income and loss of employer-sponsored insurance. The unemployed are also more likely to face serious psychological distress and ill health. Thus poor health may not only be a cause of unemployment for the chronically ill but also an effect.

Most chronic illness cannot be cured, but most can be ameliorated with proper management and support in work or educational settings. Employers and educators must cater to the needs of the chronically ill in the same way they have learnt to accommodate those with mobility, sensory and learning disabilities. It has to start with understanding of the energy-draining, pain-inducing, invisible, unpredictable and unstable nature of chronic illness. Employers should consider the special needs of the chronically ill in providing reasonable accommodation, such as time out for medical appointments; remote working arrangements; and flexible working hours. The latter, for instance, could help employees with chronic illness to avoid rush hour traffic or better manage their energy levels and the unpredictability of their conditions.

In educational settings, this may take the form of extensions of time to complete assignments and exams; alternative media for assignments; allocating a place to rest or administer medications between classes; designating note takers for missed classes; leaves of absences for programs of study without serious financial consequences; and retaking courses that have been severely impacted as a result of chronic ill health. Opportunities for studying part-time or taking reduced course loads may also help students better manage their academic studies and health problems.

The unique and compounded problems faced by the chronically ill needs to be understood and supported by employers and educators. In formulating policy we must remember that it is not the disability/chronic illness that defeats a creative and productive contribution of any particular individual. The chronically ill cannot be magicked away but the barriers they face can be torn down. This must start with increased research and prioritizing this issue. These barriers are social barriers, and it is up to us to understand and overcome them. We should not lose sight of the waste of potential talent and creativity if they are kept in place.

Between a Rock and a Hard Place

Sometimes I think about what the hardest part of living with a disability is. It's an extremely broad question; disabilities can range from scoliosis to dyscalculia to depression, among countless others, and no two people with the same condition will have the same experience. Speaking for myself, though, I think the hardest part about living with a disability is facing the biases that people often hold. My experiences with Schwartz-Jampel Syndrome are my own, not necessarily representative of anyone else, but I still hope my thoughts can provide people with another perspective on building an inclusive world.

The type of bias that I usually think of first is the negative one, which I'll use the broad term "ableism" to describe. While it's true that the United States has passed laws prohibiting (for the most part) discrimination against disabled people, no set of laws will cleanly erase a way of thinking entrenched by millennia. I don't think ableism needs to be intentional, and actually, I can't remember whether I've ever encountered purposeful discrimination.

Unconscious, subtle ableism is a very different story, though. I vividly remember walking from a neurology appointment at Massachusetts General Hospital several years ago when a stranger came up, handed me a book of Christian prayers, and left without a word. I made a very puzzled expression. I don't even believe in this stuff! was my mental reaction back then. Okay, hold it, did my walker really just convince you that I should be praying for salvation? would be a little more like my reaction now. I appreciate that this person meant well and was following his beliefs, but he made a heavy assumption about my life without first getting to know me.

That kind of unintentionally harmful interaction happens to me on an almost daily basis. I'll be walking towards a door, just about to press the open button, when someone runs over and pushes the door open for me, and then I have to be careful to not run over their toes. Why is that button there if not so that I can be independent? Or someone who doesn't know me will come up to talk, which has a reasonable chance of ending badly. If I'm unlucky, either I'll get the baby treatment ("Heeeey buddy, hooooow are you doooooing?"), they'll touch me on my head or shoulders, or if I'm with someone, they'll ignore me altogether and talk to the person I'm with like I'm not there. This school year, I've had a peer

ask me as a conversation starter whether I was a student, and I've had another ask me whether I knew what a "cello" was. I'm sure some of these examples could be misinterpretations on my part, but at the same time, I have trouble imagining the same situations happening to someone who is abled.

Again, I'll never fault anyone for meaning well. People consistently do what they think will help, but because ableism doesn't have the concreteness and tangibility of forms of discrimination like racism and sexism, awareness of the subtle harm in these actions rarely spreads. And because these actions aren't usually considered harmful, they remain widely unchallenged, and are arguably one of the last forms of discrimination to be socially acceptable.

I don't mean any of this to sound accusatory or hostile, and if it does, I apologize for it. I don't mean to criticize any individual, but instead societal norms as a whole. In fact, I struggle with my own unconscious bias against disabled people. I grew up in a very accommodating public school system, but one where the only other person with a physical disability was my friend, and many of the people with intellectual disabilities were in a separate program so that I rarely saw them. Coming to college and finding that there was an entire group of disabled people to connect with was an encouraging realization. That's why I'm sharing my experiences with bias, so that people who may not often meet disabled people, normal people with differences like everyone else, can reflect on any preconceptions—including their preconceptions of people with invisible disabilities, an extremely important subtopic.

So that's an overview of some forms negative disability bias can take, but what if we move in the less obvious direction along this spectrum to positive disability bias, the act of being inspired by someone because of their disability? Judging by that description, it sounds beneficial, and I agree. But in extreme cases, I'd argue the exact opposite, that it's degrading in a way often masked by its friendly appearance.

We've all heard about people who have been paralyzed in accidents and go on with their disability to become Paralympic athletes, and individuals like Stephen Hawking who accomplish extraordinary things by any standard of ability. These are fantastic role models. But we also may have seen social media stories about a blind person going for their morning walk with a smile on their face or an autistic high school senior participating in graduation. These may, in some cases, be amazing people. But are they necessarily role models just because they're disabled?

One day in elementary school, I was walking with my mother past the cafeteria, and I happened to make ordinary eye contact with an adult. They smiled at me. "Why did they smile when I looked at them?" I asked my mother, confused. She responded that it was because I was so cute. Which may have been the case back then, but I've continuously noticed this phenomenon, even among people my age, since that day. I won't rule out the possibility that these are people who genuinely smile at everyone because they're kind, and I really want to believe it, but I can't bring myself to fully accept that answer. I've come to an understanding that, in some cases, people smile because they see me fast-walking and doing tricks with my walker, like I do every day, and this makes them feel

uplifted that I'm so "upbeat, despite" my problems. Some people who oppose this kind of extreme positive bias call it "inspiration porn" in its online and social media context, because it objectifies disabled people doing normal activities as a source of motivation and guilt-tripping for abled people, while also implying that disabled people are all the same regardless of their condition: heroes who can do anything if they only "try hard enough."

I'm not a "hero" for living with my disability, and no, that's not modesty. I want to live my life and play video games and pursue my interests, and I think anyone in my position would do the same. I don't complain about surgeries after forty-seven of them and plenty of admittedly horrible times, and while I'm more resilient than some people, no, that's not stoicism or "strength"—because what does complaining out loud accomplish when doctors are working to help me, and I just need to eat, take pain meds, and sleep to become even healthier than before? I'm not a tirelessly cheerful person who cracks jokes when things look tough, because no, I'm not a fictional character. I hide it, like most people do, but I've experienced my share of emotional breakdowns alone late at night. No, I'm a person.

To be clear, I don't believe any of this is a black-and-white issue. No one should control what inspires another person—for transparency, my biggest inspirations are video game characters: a fifth grader struggling with depression named Geo Stelar, a defense attorney named Apollo Justice, and an archaeologist named Professor Layton—and it is never "bad" to simply be inspired by a disabled person doing normal things, because they can be inspirational like anyone else, and people need inspiration. At the same time, we need to distinguish why a disabled person inspires us, and how that inspiration influences our perception of disability. Each individual must answer these questions for themselves.

In summary, then, I believe there's a spectrum of generalizations and biases about disability, ableism on the negative end, objectification and over-idolization on the positive. This scale reminds me of the myth of Daedalus and Icarus, in which Icarus must escape over the sea on artificial wings made of feathers and wax. His father Daedalus warns him not to fly too close to the sea, lest the moisture weigh down the wax, or too close to the sun, lest the heat melt the wax. Icarus doesn't listen, of course; he flies too close to the water, notices his wings becoming wet, and in panic, overcorrects by flying too close to the sun. Icarus' wings dissolve, and he falls back into the sea.

I'd argue that by emphasizing the importance of maintaining a middle path, the myth of Daedalus and Icarus provides a helpful framework for considering and addressing disability bias. If the sea represents ableism, and the sun objectification through extreme and unwarranted praise, we need to fly a course through the middle of the sky. It's not easy. The gravity of thousands of years of misconceptions and



stereotypes inevitably pulls us down towards ableism, intentional or unintentional, and when we discover that our wings are waterlogged, our natural inclination is to pull up towards the sun to dry ourselves out. But maybe we misjudge our trajectory, and in our effort to avoid traditional discrimination, we instead adopt a different kind, one that reduces disabled people to their everyday actions that are seen as heartwarming and heroic. We may end up down at the sea that we left behind.

To change this situation, we need to start small by changing ourselves. I believe that we're already on course to our destination, and that we have everything we need—everything except a map, that is. We know how to steer. These are ongoing processes, but people are working to create more dolls that kids of racial minorities can see themselves represented in, and people are trying to create an environment in which scientists who are women are no less respected than scientists who are men. We know how to identify obstacles. Awareness about discrimination based on sexuality and age, for example, has started to take hold relatively recently. But we need to learn to combine these two skills, to outline a middle path between sea and sky that acknowledges and addresses disability bias. We need to learn to learn. We need to learn to talk with disabled people as people, without awkwardness or excessive caution in choosing words. And I hope disabled people who feel comfortable will encourage people to ask them questions. Maybe it's anticlimactic, but I don't see any revolutionary policy reform addressing the omission of disabled people from conversations about universal respect, equal treatment, and intersectionality. I see a solution that starts with each and every one of us, myself included, in which we actively learn about other people and treat them as we already treat other people. We've made progress with discussions about race, ethnicity, gender, sexuality, religion, immigration status, and marital status, among many others, and I trust we can do it with disability too, not instead of other movements, but in addition to them.

In Geo Stelar's second video game, *Mega Man Star Force 2*, Geo's mother gives him advice, a quotation from his missing father, about facing responsibility while carrying a heavy burden: "Whether I succeed or fail, it doesn't matter; it's whether I have the courage to try. Even if I should fail, my courage might inspire someone else to try. And even if that person fails, their courage will inspire the next one." I don't expect that people will eliminate disability bias soon, or maybe even ever. It's ingrained in our cultures, and only an extraordinary event would change that. But I believe what people need to learn as they chart their flight is that that doesn't matter; the cultural grounding is true, but irrelevant. What appears like an insurmountable societal problem is an issue we each have power over, one that we can work together to solve, with no group opposed to another. But under such a heavy burden of change, what matters is that people try; because that's when others try along with them, and that's when we create possibility. Our flight to the horizon can waver, as long as it always aims straight.



How IDEA Opened the Door to Access to Higher Education

With the passage of the Education for All Handicapped Children Act in 1975 and eventually the Individuals with Disabilities Education Act in 1990 and 2004, the United States saw an increase in access to K-12 education for thousands of students with disabilities across the country. One of the key pillars of the IDEA (2004) was ensuring that to the maximum extent appropriate students with disabilities were to be educated with their nondisabled peers (IDEA, 2004). Establishing the norm that students with disabilities should be educated with their nondisabled peers paved the way to new educational opportunities for students.

Fast-forward 15 years later and we have an entire crop of students graduating who have the skills necessary and the will to continue their education. Specifically, students with intellectual and developmental disabilities (IDD) who were systematically excluded from institutions of higher education for decades. We have more students than ever graduating high school with a diploma but do not have a program that will fit their needs and personal goals. The higher education system has not kept up with the pace of these changes leaving students stranded and unable to continue their educational trajectory after graduation like so many of their peers. What does that next step look like for these students? How do we ensure that their disability does not become a barrier to their next step in life?

Why College Needs to Be the Next Frontier for Disability Rights

Employment and Education Statistics for Individuals with a Disability

For a student with a disability, the transition from their K-12 education to their post-secondary pathway of choice can be especially difficult. The services offered to help students with disabilities enter a college program vary drastically across districts and can be scarce, creating a difficult transition for students and families. Students with IDD accessed some sort of college at a rate of less than 40% compared to about 80% of their peers (Zafft, et. al, 2004). Unfortunately, transition plans developed in high school rarely list post-secondary education as a possibility for students with IDD (Papay, Grigal, Hart, Kwan & Smith, 2011). The rate of individuals with a disability that have some college or associate degree was 29% compared to a person with no disability at 72% (NCES, 2017). As more and more states are focusing on increasing college attainment, they should shift their focus to ensure all students, no matter their ability level, have access to a high-quality postsecondary pathway.

Similarly, alarming statistics exist when looking at post-school outcomes for individuals with disabilities. The unemployment rates for individuals with a disability (8%) was twice that of an individual with no disability (4%) in 2015 (NCES, 2017). Employment rates for adults with individuals with intellectual and developmental disabilities (IDD) aged 21-64 remain around 34% compared to 76% for adults without disabilities (Siperstein, Parker, & Drascher, 2013).

Of adults with IDD who were working, only 18% were competitively employed with the majority of the remaining individuals working in a sheltered setting (Siperstein et al., 2013). Many states have waitlists to receive employment services in the tens of thousands (National Report on Employment Data, 2018). Postsecondary education is often a pathway to higher employment rates and higher wages throughout a persons' lifetime (NRC, 2015) yet we are not creating those same opportunities for individuals with disabilities.

Higher Education Opportunity Act of 2008 – New Pathways to Higher Education

The Higher Education Opportunity Act (HEOA) of 2008 created a pathway to new opportunities for individuals with IDD and their access to college. There are three policies within HEOA that drastically shifted post-secondary education (PSE) for individuals with IDD. It created new pathways to financial access, determined a definition of Comprehensive Transition Programs, and allocated funds to develop model Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) and a national coordinating center.

Found in Title VII, Part D, Section 760 of HEOA the term Comprehensive Transition Program (CTP) means:

A degree, certificate, or non-degree program that is-

- offered by an institution of higher education
- designed to support students with (intellectual disabilities) who are seeking to continue academic, career and technical, and independent living instruction at an IHE in order to prepare for gainful employment

- includes an advising and curriculum structure; and
- requires students with intellectual disabilities to participate on not less than a half-time basis, as determined
- by the institution, which such participation focusing on academic components.

This was the first time that the Federal government identified specific components that should be present in a post-secondary education program that serves students with IDD. The legislation indicated a focus on inclusive academic access with the end goal of competitive employment (Grigal, Papay, Smith, Hart, & Verbeck, 2019).

The second landmark component of the act allowed students with IDD to be eligible for Pell Grants, Supplemental Education Opportunity Grants, and the Federal Work Study Program. Students were previously excluded from this sort of financial aid due to the fact that some students lacked a regular high school diploma and did not meet an "ability to benefit" test (Lee, 2009). This was a huge win for students and awarded a new opportunity for learning to thousands of students (Grigal et. al, 2019). Despite the shifts in federal law, the variability in the costs of programs leaves many low-income students without an accessible option in their area. The last component of the HEOA was the funding and creation of the Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) in 2010. This policy enabled institutions of higher education (IHE) to create high-quality inclusive models of CTP (Grigal et al., 2019). Over a 5-year funding period, the TPSID offered funding to jumpstart programs at IHEs across the nation and it also created a Coordinating Center that provides technical assistance to institutions with transition programs (Department of Education, 2019). This grant created CTP programs at 58 college campuses in 23 states in the first wave of funding and an additional 23 more in the second funding period (Grigal et al., 2019). The aforementioned changes in legislation have opened pathways for individuals with IDD that were not possible before but many states have yet to ensure that every student who would benefit from a CTP program has access to one.

Comprehensive Transition Programs and Why They Work

Status of CTP Programs

Institutions of higher education (IHE) have offered transition programs for decades (VanBergeijk, 2011) but the passage of the HEOA in 2008 offered technical assistance and funding to establish stronger programs. They also focused on ensuring that programs were more inclusive and required students with IDD to participate in courses and activities with their non-disabled peers (VanBergeijk, 2011). The creation of these programs is pivotal in creating better post-school outcomes for individuals with disabilities. Individuals with IDD who participated in one of the CTP have experienced better post-school outcomes including higher levels of employment, increased wages, and extended social networks than peers who did not have a postsecondary education (Hart, 2006). Students who completed the program earned on average 73% in higher weekly income (Migliore, Butterworth, & Hart, 2009). Similarly, a higher total number of years attending a CTP was associated with higher odds of obtaining paid employment at some point (Grigal et al., 2019).

Students who received a non-degree credential have shown higher earnings than those who participated in a typical vocational rehabilitation program or had a high school diploma (Carnevale, Rose, & Hanson, as cited in Grigal et al, 2019). With the help of the HEOA, by 2013 48 out of the 52 TPSID programs offered some type of credential to students. Researchers found that earning a credential that was awarded by a TPSID program doubled the odds of gaining competitive employment at exit (Grigal et al., 2019). States should start to focus their attention on ensuring that more institutions of higher education are offering authorized credential to help create a pathway to a more financial independent life for individuals with disabilities.

Best Practices for Comprehensive Transition Programs

Researchers at Think College, the organization established by the HEOA to offer technical assistance to states and institutions, found five significant predictors of paid employment at the exit of the program (Grigal et al., 2019):

1. Earning a credential that was awarded by the IHE- Credentials that were awarded and recognized as an official credential by the IHE's governance structure was a major predictor of employment at the exit. These credentials are more widely accepted by employers than program-specific certificates.
2. Attending a 4- year IHE- Students who attended a program housed in a 4-year IHE increased the odds of having a paid job compared to students who attended a program at a 2-year IHE.
3. Paid Work Experience- Students who obtained paid employment while enrolled in a CTP program were 15 times more likely to have a paid job at the exit. Of the students who held a job during the program, 60% continued working in that job after exiting the program.
4. Living in IHE Housing- Living on campus for part of the program had higher levels of participation in social activities, attending organized events, and attending sporting events suggesting that housing fosters socialization with peers. The study found that students living in IHE housing were less likely to have paid employment at exit. More research is needed to understand the reasons for this but researchers proposed the transition back to a student's home community can create another hurdle for students obtaining a job.
5. Years Attended- Higher total number of years attending a program was associated with higher odds of obtaining paid employment. This often resulted in more extensive career support and community-based instruction over the extended time period.

It is obvious that enrollment in a CTP can have positive impacts on a person's life as they age. These programs not only assist individuals with a path to paid employment but they also assist in helping individuals to gain access to a larger community. Since the passage of the Americans with Disabilities Act in 1990, there have been major strides for individuals with disabilities gaining access to new parts of the community. Individuals with disabilities are driving at higher rates than ever and are living independently at the same rate as the general population of youth ages 18-24 (NLTS2-Wave 2, 2006). Creating these pathways for students with IDD can help put them on a pathway to a more independent and financially stable life.

Current Obstacles for CTP Programs

Despite the increase in transition programming at institutions of higher education across the country the path to college continues to have seemingly endless obstacles for many students. Where a student lives is a major factor in determining if they have access to these programs. For example, there are currently 24 states that only have 1 or 2 programs for the entire state (Think College, 2019) making the possibility of attending one of these programs almost impossible if you are not lucky enough to live in a region with a program.

The pathway to alternative education programs for students with more significant needs can be even more tumultuous for low-income students, as there are very few CTPs and those that do exist, can be extremely expensive making them inaccessible to students from low-income backgrounds. Throughout the United States, there are currently 282 college programs for students with IDD but only 101 of them offer Federal Financial Aid. It is difficult to estimate the average cost of CTP programs but prices can range from \$1,000 to upwards of \$25,000. It is obvious that the max Pell Grant which is \$5,500 per semester will not be enough for many students. Many of the fees do not cover Room and Board, additional fees, textbooks, or travel. It is important to note that students enrolling in these programs are not eligible to receive student loans from the federal government making some programs largely inaccessible if a student's families do not have the means to pay out of pocket.

Next Steps for States

It will be important with the reauthorization of the HEOA that state work to take advantage of the grant process to develop additional programs. The state of California can be used as an example of how to respond to the current need and potential changes in HEOA by creating partnerships with Vocational Rehabilitation services and The California Community Colleges (CCC). California created the Community to Career (C2C) programs. They established five pilot C2C programs that would offer three-year programs aligned with the requirements of HEOA and met the following requirements: offered at a college, support students with IDD who are seeking PSE, include guidance and advising, including at least 50% focus on academic opportunities with students without disabilities, and led to competitive employment outcomes as indicated in the contract (Raynor et al., 2016). The state allocated \$250,000 per year for four years and created a unique partnership that created a partnership with the Vocational Rehabilitation services that were offered in conjunction with the programming at the school. The CCC worked in conjunction with UCLA to serve as a consultant to provide both advice on program development and professional development (Raynor et al., 2016). The program saw great success with increased job skills (resume building, job searching skills, etc.), paid employment during the program, and an increase in wages for those who were working (Raynor et al., 2016). California's C2C initiative can be used as a model for how to scale these programs nationwide.

Conclusion

As we continue the national discussion about college for all, we need to make sure that we are truly meaning all. Students with intellectual and developmental disabilities have a right to these educational opportunities. We have the framework and research to back these practices up but need to work to make sure that states and institutions of higher education are following suit and creating more CTP programs.

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Dancing in the Dark; My Life and Disability

When I first started to think about how I might construct a piece of writing on my relationship to disability, a number of people, places, and topics flooded my mind and my heart. For months, I have reflected on the various ways my life has been touched by disability, for better or for worse. I have been lucky to connect with disabled students at Harvard from all walks of life. As the 2018-2019 Disability Disclosed co-chairs wrote so eloquently in last year's issue, "each and every person in any disability community experiences disability differently."

Chronologically in the story of my life, I think first of my brother, who lived with a number of physical disabilities from his birth until his untimely death during our childhood.

Next, my mind most often wanders to my own struggles in school; from the flourishing of my intellectual curiosity during my time in a non-traditional classroom, to the squelching of it during my adolescent years, and the punitive responses to my academic failings in traditional learning environments. Where does the disability end, and where do I begin?

In more optimistic reflections on my childhood in a public school system, I reflect on my time during elementary and middle school in integrated classroom spaces, in which students with varying abilities and disabilities learned together; sometimes for "special" subjects like

music and gym, but also for courses like social studies and science. Still, in these integrated learning spaces, I felt pressure to "pick;" did I want to sit and eat lunch with the students with whom my brother and I identified, or did I want to sit with my "normal" friends? There would be consequences either way, I learned.

In my adult life, I find that describing life with chronic illness is perhaps the most difficult thing about it. In many ways (or at least, in my case) it is evasive and enigmatic. Identifying it, naming it, diagnosing it, finding the right care providers...it is, to borrow the words of the singer-songwriter Bruce Springsteen, like dancing in the dark. To carry on with normal activities requires a very intimate and particular form of self-care. It requires a knowing of one's body that goes beyond even the touch of a medical professional. It is a kind of knowing that alerts me when something is wrong, even if someone on the outside could not see it. It is the I need to lay down right now feeling that will unapologetically interrupt any social engagement, pressing deadline, or 8-hour shift.

The American healthcare system scarcely allows for any kind of labored investigation into pains that cannot be named. Our system is not only an impatient one, and an overcrowded, overworked one, but an expensive one. The journey to find relief is long and arduous, and each stop along the way will come with a large price sticker. For those without insurance, the

journey may not be worth taking in the first place. It becomes monotonous and exhausting, not only the presence of the illness itself, but the seeking of care and treatment. Like any appointment, it almost always goes something like this: I give my name and my birthdate at the counter. I sit down on a plastic chair and wait. I am called in, I will be weighed and measured, and my blood pressure will be taken. More plastic chairs. More waiting. Sometimes I have to remove my clothing, perhaps for a doctor I've never met before. By the time the doctor arrives, I'm nervous, but I feel ready to present my case. Perhaps unlike other doctor's appointments, I have notes. I have pictures and videos of my symptoms flaring up. I have records from other doctors, spread all over the country through different chapters of my life. I have printed lab results. I have prescriptions from years past. This time could be it; this could be the beginning of figuring this out, I think. My dad's voice joins mine. We just have to keep at it. We just have to find someone who will listen. I think he feels guilty. He knows it is his genes that fail me. But I am almost always hopeful.

"What brings you in today, Elizabeth?"

Where to begin? No way to know...but I do. I take a deep breath, and begin five years ago. How to recount five years of bodily pain in just a few minutes? I try my best. I start with the first morning I woke up, five years ago, and felt that my body was not the same. Here's what happens, here's what I've tried.

Here's what I've stopped eating. Here's what I've eaten more of. From ophthalmology to rheumatology, I've been there. Here's how I've tried to control my environment. Here is everything I have done. I have done everything. Take it. Heal me.

And then I hold my breath.

"Hmm...that really is strange. I can't imagine what could be wrong with you."

"Are you on your period?"

"Well, it sounds like you've been living with this for a long time. A couple more months shouldn't hurt you, until we can get another appointment."

It stings. I hold my breath again and hope that he doesn't ask me if I've seen a psychiatrist. Please don't think I'm making this up. My hopes come crashing to a halt again, as another person with a wall of impressive degrees looks at me with bewilderment. They take more blood. They take more urine. They set up another appointment, and then I am free to go. If I've managed to hold back tears for this long, they'll certainly come now. Springsteen's raspy voice comes through my tangled headphones, making me feel like I'm in my parent's kitchen.

Hey there baby, I could use just a little help... You can't start a fire without a spark. This gun's for hire, even if we're just dancing in the dark.

We have for so long been afraid of the word disability. “We are all disabled,” I’ve heard in academic settings. “Disability is a spectrum.” The ease with which we move from identifying structures as the problem, to assigning everyone in the world a disability is baffling. I’ve found that this often results in an identity-seeking scramble, where one attempts to place oneself somewhere on this “spectrum.” Where do I fit, between the letters that look like numbers and the illness that won’t get better? Where do I fit, between my brother and my friend with terminal cancer? Where do I fit between my friends and family members who are blind, who use wheelchairs, who have Down syndrome? Can we all possibly be part of the same community?

I’m not certain that I have answers to these questions. If I did, this piece would certainly be a lot longer. I do know, definitively, that this is a community with a range unlike any other. It is a community that says, “come as you are, there is a place for you here.” A conversation about disability, like so many big conversations, cannot be without acknowledgement of race, class, and gender. We may feel compelled to draw more lines, to separate ourselves more, to believe we have nothing in common. I have found that disability can be both a uniting and dividing force, in this way. What could we possibly have in common? I can see with my eyes, and you cannot. You are hearing, and I am not. I can walk without support, and you cannot. You can complete your multiplication tables in a minute. I will take an hour.

I believe that we are unified when we recognize each other’s lived experiences as wildly different. They are different, and yet equally valid. Our stories hold equal importance, though the wounds they carry may look nothing alike. When Springsteen sang about “dancing in the dark,” he lamented a life he felt was devoid of meaning. The singer reaches out for meaningful companionship while wishing that he could remedy his imperfections (Man I’m just tired and bored with myself...I wanna change my hair, my clothes, my face). What can we do about this melancholic desire to fit in? How can we find meaning in the parts of ourselves that don’t quite make sense? Must we change ourselves in order to find community? I think of the “spark” that Springsteen writes about as (big C) Community. And, as the denim-clad singer songwriter tells us, we can’t start a fire without a spark. Despite our varying needs, abilities, and methods of communication, we need one another as allies and advocates. We must work to amplify one another’s voices, support each other’s movements, encourage each other’s activism. There is a place for our bodies, there is a place for our languages, there is a place for our knowledge. We will press on, together, even when we don’t have all the answers, even when the lines are blurry and the labels are messy. Even if we’re just dancing in the dark.





This publication cover is printed in a warm colorful texture, with a white title on top of braille lettering reading "Disability Disclosed".

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