

Breaking barriers for those with hidden disabilities



By Isabel Carrera Zamanillo

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Chronic illnesses, mental health issues, and other hidden disabilities can be debilitating, especially in combination with stigmatization and lack of proper accommodations. Breaking barriers in academic systems for those with hidden disabilities demands that personal, institutional and organizational ableist biases are overcome, writes Isabel Carrera Zamanillo.

As a Mexican female environmental scientist with hidden disabilities, I have first-hand experience of many different forms of discrimination in academic and professional spaces. Discrimination that led me to question whether there really is a space for people like me to thrive in STEM settings.

I was born in Mexico City. Even at a very young age I had a love of learning, and I also practiced sports at a competitive level. Like many others, I took my privilege for granted and never thought about issues related to accessibility. However, on my fourteenth birthday, I started experiencing multiple inexplicable health issues that turned my world upside down. Multiple visits to physicians of many different specializations, more than a dozen pills per day to alleviate different ailments, and the need for constant assistance from my family to be able to attend school all became the new normal. Within a very short period of time I transformed from an outstanding student and athlete to a 'problematic' teenager. By the end of my first year of college, I was diagnosed with dysautonomia of the central nervous system, fibromyalgia, and chronic depression. It is important to say that those first two conditions (and arguably all three) are still poorly understood by modern science, and that the third is also a common source of stigmatization.

As with many other people with hidden disabilities, the lack of obvious signs of illness or physical disability meant that I started being

tagged as lazy, hypochondriac, crazy, and even Machiavellian. This harassment and devaluation led me to think I had two choices: give up and let others define me with their labels, or fight to live as normal a life as possible within my limitations and try to define myself. My decision to study biology at the Universidad Nacional Autónoma de México (UNAM) was the first step in a journey that is still ongoing. Despite many difficulties, my journey took me to completing a PhD in Environmental Sciences at the University of Washington, and going on to teach at UNAM, University of Washington, and Stanford University. Currently, as the Diversity, Equity, and Inclusion Assistant Director at the Stanford Doerr School of Sustainability, I work every day to reclaim a space in academic settings for myself and others, while challenging ubiquitous ideals of universalism and objectivity rooted in oppressive ideals and practices.

With the ever-increasing number of technological solutions and inclusive frameworks, such as universal design, there are now many tools that can increase accessibility in all STEM areas, and especially Earth and environmental sciences, which is currently one of the [least diverse](#) fields around. However, in order to promote institutional change, persistent forms of ableist biases, prejudice and oppression need to be addressed at individual, group, and institutional levels. Here, I provide some insight into the barriers and stresses that people with hidden disabilities can face in academia, highlight the skills and advantages a diverse workforce can bring, and pinpoint ways that colleagues, institutions and organizations can actively support and accommodate researchers with often invisible needs.

Provide support

The reality is that, in general, institutional efforts to provide accommodations for people with disabilities are rooted in a deficit perspective of disability. The level of competency and productivity in those with a disability is still questioned, while their skills such as resilience, adaptiveness, or determination are

not valued. Therefore, those with a disability are often denied equitable opportunities as they often have to work harder to make up for any differences with their peers.

For my first year of undergraduate, I did not have a definitive diagnosis to share with my professors and university administrators, which meant that many of my absences seemed unjustifiable to them. Even after I got a diagnosis, due to a lack of awareness and understanding regarding my conditions, I had to rely on my own resourcefulness to ensure I could participate in courses like the rest of my classmates.

I accomplished this participation largely by requesting special accommodations. However, the need to go to extreme lengths to prove the need for these accommodations was exhausting, and took even further time out of my studies. For years I had provided hospital bills, results from lab tests and exams, and letters from doctors. All this left me with the feeling that my personal privacy and dignity were being violated. Even after all this effort of securing medical proof, the provision of accommodations for people with hidden disabilities still often heavily relies on the good faith of individual instructors, administrators, or managers. However, that individual good-faith does not always exist.

System-wide support to people with disabilities needs to be rooted in recognition of personal, organizational, and institutional ableist biases, as well as an intentional and on-going appreciation for the benefits of diversity. Institutions must ensure that they have established support systems in place, so that individual needs are met without increased stress to the person and without them needing to rely on the good-faith of another individual.

From adaptation to active advocacy

I think it's quite possible that the stress that came from constantly struggling over barriers to my career contributed to a decline of my health. By the third year of my undergraduate degree, I could not do fieldwork without my mother having to travel with me, since the university could not provide health insurance

to cover my conditions. Hypersensitivity to both chemical fumes and light became a barrier to working in laboratories. Frequent hospitalizations, including a cardiac arrest, sometimes requiring long hospital stays for weeks at a time, created further disruptions to my studies.

Many suggested that the best option was just to resign and stay at home. However, some of my professors helped me discover new paths in science where I could continue my journey without threatening my health. They became my advocates and allies, listening to me describe what I wanted to do, sharing their knowledge, and providing support through learning resources and letters of recommendation. Part of this process involved working closely with my doctors to co-design my treatments, so I could learn how to manage my own and others' expectations.

A key insight for me has been not merely learning to understand my own limitations, but to find ways in which my experiences are strengths. To make STEM areas more inclusive, it is necessary for every individual to challenge the idealized version of a scientist, this is, the heteropatriarchal and ableist perspective,

and recognize that the multifaceted nature of scientific research requires a diversity of perspectives and experiences. A disability does not have to be seen as a burden or a source of shame or retaliation.

Over time, I have learned ways to advocate for myself and others by increasing disability awareness and promoting better accessibility. However, it should not be up to the minority to fix the problems created by the majority. Bystanders must transform into active allies by actively acknowledging forms of oppression and exclusion, sharing power, and adopting and demanding more inclusive policies, practices, and spaces. Being an ally does not mean to speak on behalf of, but to stand by the side of.

Policy makers must listen to a broad range of experiences to design more inclusive policies and practices, making meaningful actions to prevent the self-doubt that often comes with having a marginalized identity. I do not claim to know all; organizations such as the [International Association for Geoscience Diversity](#), the University of Washington's [DO-IT \(Disabilities, Opportunities, Internetworking, and Technology\)](#) program, Carleton College's

[ADVANCEGeo](#) partnership, and the Global Applied Disability Research and Information Network ([GLADNET](#)), have created a plethora of resources to inform and support the creation of welcoming spaces for people with disabilities in the geosciences and academia in general.

The implementation of equitable and inclusive practices that break the barriers to academic and professional areas must not only rely on the decisions of people in leadership positions. Individual actions are so crucial to the development of an inclusive culture, or the lack of it. Passivity entails complicity. This piece is an invitation to reflect on your role in the creation of spaces where people with disabilities can thrive.

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