

Mentors as Allies for Disabled Scientists

Emilio I. Alarcón*

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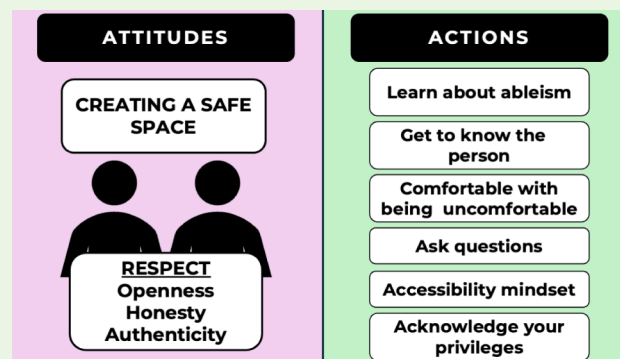
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ABSTRACT: Close to 28% of the population in the United States and Canada is living with disability, yet despite this prevalence, persons with disabilities remain mostly absent in biomedical research. While the role of mentors has been demonstrated to be effective in increasing the number of women and other groups in biomedical research, mentoring disabled scientists remains a gray area. In this short perspective, I share my personal experience as a person with a disability who was mentored by a nondisabled person, who ultimately became an ally.



KEYWORDS: *mentors, ally, disabled scientist, biomedical research, disability, healthcare*

■ DISABILITIES IN NUMBERS

While disabilities may appear unfamiliar or distant to some, statistics reveal that approximately 16% of the global population lives with a disability.¹ In countries such as Canada and the United States, this figure approaches 28%.^{2,3} However, individuals with disabilities constitute less than 5% of biomedical researchers in the United States.⁴ This disparity is particularly pronounced in the biomedical and healthcare sectors, where the inability of individuals with disabilities to perform specific tasks in the same manner as their nondisabled counterparts, ranging from using a pipette to articulating critical thinking or conveying ideas, has been employed as an exclusionary tool. This stark reality has contributed to the negative perception of biomedical and healthcare research as the ultimate solution to “cure” disabilities or, even more problematically, to entirely prevent their occurrence. Consequently, biomedical and healthcare literature frequently employs terms such as “patients suffering from” and “disability burden,” which perpetuate subtle discriminatory discourse embedded in academic traditions that promote the notion of “curing” or eliminating disabilities. As a direct consequence, both health and biomedical research systems, founded on ableist assumptions and principles, restrict access to individuals with disabilities, preventing them from pursuing scientific careers and contributing unique and transformative perspectives. Regrettably, for disabled individuals, there is no established pathway from primary school to higher education, as many young, talented individuals with disabilities are discouraged from even considering a career in science.

■ BARRIERS FOR DISABLED SCIENTISTS

In this contribution, I will outline some of the nonphysical barriers that biomedical researchers, particularly biomaterialists, with disabilities encounter when pursuing academic research and work. Individuals interested in delving deeper into the concept of ableism in academia are encouraged to refer to Timothy Dolmage’s book titled “Academic Ableism,” which is available at no cost in various formats, including an audiobook.⁵

In Canada, a recent environmental scan conducted by the Canadian Institutes of Health Research (CIHR) revealed that individuals with disabilities encounter discrimination and biases when disclosing their disabilities.⁶ The standard funding structures and systems also fail to address the needs of individuals with disabilities, ranging from inaccessible Web sites to guidelines that are not provided in alternative formats.^{6,7} Additionally, in grant panels, biases, both conscious and unconscious, perpetuated by peer reviewers based on ableist metrics of excellence serve as significant gatekeepers, hindering disabled scientists from securing funding.⁶ The recruitment processes employed by universities, unfortunately, often lack accessibility considerations, leading to the systemic exclusion of individuals with disabilities from academic positions.⁷ As a specific note, biomedical work culture is closely associated with

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Table 1. Some Tips on What Can You Do as a Nondisabled Scientist if You Are to Mentor a Disabled Scientist

Action	Why does it matter?
Learn about ableism and other practices implemented throughout modern history.	Familiarize yourself with ableism and other related practices that have shaped the modern history of persons with disabilities. ⁹
Get the mentee to know you as a person.	Persons with disabilities tend to be asked too many questions about themselves. Showing yourself authentically does not take away your professionalism. Think that persons with disabilities have been historically examined and “studied” on.
Learn to be comfortable with being uncomfortable.	Some of the stories you will hear from persons with disabilities are deeply unsettling. However, those are an essential part of our journeys.
Do not be afraid to ask questions you were told you should not to.	Most knowledge in the literature about living with a disability is written by nondisabled persons. This narrative contributes to the perception that being disabled is to be fixed or entirely prevented. However, you will be surprised about how diverse the experiences of living disabilities really are.
Set your mind to thinking about accessibility rather than accommodations.	Accessibility allows individuals to achieve a goal or complete a task independently on how that is done. Accommodations simply mean achieving a goal or completing a task by providing the “means” for the disabled person to do that in the same way nondisabled persons do. The latter is, unfortunately, the gold standard for most institutions. Note that accessibility does not mean making things easier or lowering standards for disabled persons.
Acknowledge your privileges.	Understanding your privileges does not take away what you have earned by working and studying hard. Understanding your position of privilege(s) allows you to decide how to use those privileges to level the field for persons with disabilities.

extensive networking and public engagement, which may not always be feasible, within the context of our societies, for individuals with disabilities.⁸

LIVED EXPERIENCE

As a disabled scientist, my journey has been one of navigating a world that merely accommodates my needs. My disability, which can be “hidden,” has enabled me to “chameleon” and “hyperperform” the so-called academic “excellence.” While this ability to conceal my disability is a privilege, everyday tasks such as attending conferences, reading emotions, dealing with poorly designed grant application instructions and portals, reading scientific articles, attending multiple daily meetings, and navigating social norms present significant barriers for me.

During my recruitment as an investigator, I was fortunate to be paired with a mentor who profoundly impacted my professional journey. Initially, I harbored skepticism due to my mentor’s absence of a disability. However, as we transcended the professional aspect of our relationship and developed a deeper understanding of each other, my mentor unveiled his human side, fostering a comfortable environment in which to disclose my disability.

My mentor dedicated significant time to elucidating concepts that might be intuitively understood by others such as the intricacies of the administrative system within my institution and the significance of participation in scientific societies. Over time, my mentor became my guiding light, assisting me in navigating the complexities of academia.

Furthermore, my mentor demonstrated exceptional support. During one of our meetings, I expressed my challenges in comprehending grant guidelines provided by funding bodies. My mentor inquired if making these guidelines word-accessible would be beneficial, and I enthusiastically agreed. Consequently, a few weeks later, my institution implemented the accessibility of these guidelines. A month later, I had the opportunity to engage in a meeting with my institution’s leadership to discuss the potential benefits of implementing timelines for applications and providing additional time for grant proofreading to support young investigators.

The transformative power of mentorship emerged from the mutual respect that developed between my mentor and me. This respect enabled my mentor to perceive beyond my disability. Our meetings, typically held outside an office, we commenced with casual conversations about family and summer/vacation

plans. My mentor’s ability to instill a sense of belonging within my field, Biomaterials, remains a profound gratitude.

Our mutual respect coupled with authentic institutional commitment to accessibility has fostered an inclusive and supportive environment that has benefited all. While acknowledging the ongoing need for improvement, we have made significant progress since my recruitment. I proudly say that my institution created a “safe” space for me, and my mentor and I mutually enriched each other’s lives.

At my institution, I am not penalized for not attending many conferences annually or for occasionally seeking quiet time during meetings. I am not perceived as a hero but as an individual whose unique qualities contribute to the institution’s success. Furthermore, I believe that I, as a person, have contributed to de-ableism my institution, albeit in a modest manner, resulting in a more prosperous, accessible, and “human” environment for everyone.

Persons with disabilities are not inspirational, heroic, or even worthy of celebration. We are the “survivors” of a disabling society. The few who have achieved success in this field acknowledge that our journeys have been marked by harrowing stories, despair, and frustration. Every day, I reflect on the many talented individuals with disabilities who aspired to contribute to biomedical or healthcare research only to have their dreams thwarted by the system. We have lost an abundance of talent and continue to lose it.

. I sincerely hope institutions and governments will praise-celebrate-heroically-portray less the very few disabled scientists the system has let through and focus on co-creating strategies to sustainably increase the representation of Persons with disabilities in biomedical research.

If you are a nondisabled scientist reading this and encounter a disabled scientist in the future, I strongly encourage you to do what my mentor did: get to know the person, see beyond the disability, and become an ally, we need more of that! We are all part of the much-needed narrative shifting toward inclusion of persons with disabilities in research.

When I stand in a classroom, I remind my students, from my privileged position, that persons with disabilities do not “suffer” because of disabilities but because of the disabling society in which we live in.

As a final token, I have created a short table (Table 1) with some key points on “what can you do as a nondisabled scientist if you are to mentor a disabled scientist,” which I hope is useful for those willing to be the much needed change we need.

AUTHOR INFORMATION

Corresponding Author

Emilio I. Alarcón – *Bioengineering and Therapeutic Solutions (BEaTS) program, University of Ottawa Heart Institute, Ottawa, Ontario K1Y4W7, Canada; Department of Biochemistry Microbiology, and Immunology, University of Ottawa, Ottawa, Ontario K1H 8M5, Canada; Brain-Heart Interconnectome, Ottawa, Ontario K1N 6N5, Canada; Email: ealarcon@uottawa.ca*

Complete contact information is available at:

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Notes

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