



Shifting Blind
Identities in
Higher Education
Stories of Selfhood

ALISON COOK-SATHER, editor



Shifting Blind Identities in Higher Education



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Edited by
Alison Cook-Sather



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INTRODUCTION

Unfolding Stories

Alison Cook-Sather

I begin with some alt text for the front cover of this book. Top center is a nearly full dark black circle, the uppermost arc cut off by the upper edge of the cover. Extending in every direction from the circle's circumference are bright orange-yellow rays, the color of pollen or sunlight. These rays blend into innumerable thin, bluish-white strands that then blur into a soft blue background. The image could be an artistic shot of a flower's pistil and inner petals. It could be a long-exposure photograph of a star trail. It is, in fact, a close-up of

an eye's pupil surrounded by its iris. Below the image, against the soft blue background, the book title is in large white letters: *Shifting Blind Identities in Higher Education*. The subtitle, *Stories of Selfhood*, is in soft yellow letters. At the very bottom of the cover, in dark blue letters, are my full name and the word "editor."

The way an image is perceived, either through directly observing it or through hearing it described, can yield numerous first impressions. Those impressions can shift when the mind moves from preliminary thoughts based on previous experiences and associations and in response to more information and understanding gathered over time. By opening the introduction to this collection of essays through evoking an image such as this, I hope to invite a consideration of perception and the ways that first impressions need to be contextualized, questioned, expanded upon, and sometimes replaced altogether—to be shifted. This book invites readers to consider the multiple meanings of and possibilities for shifting blind identities in higher education through learning from the stories of students and faculty who experience blindness or low vision.

Each essay in this collection addresses in its own way the following questions in relation to a context—higher education—that is “oriented towards the use of the eyesight” (Sahasrabudhe & Palvia, 2013, p. 1). First, what is the relationship between “seeing and selfhood” (Mintz, 2002)? Second, what choices do students and faculty make about how they experience and represent the intersections of their vision

condition and other dimensions of their identity? And third, what do authors wish others to understand, consider, let go of, or embrace regarding the experiences of navigating higher education with blindness or low vision? These are some of the questions that I, as someone who is sighted, have come to learn are central to students and faculty with blindness or low vision, including my daughter, Morgan, who, at the time of this writing, was about to embark on her final year as a college undergraduate.

The challenges of navigating higher education with blindness or low vision are complex and relentless, and few explore the possibilities that these conditions afford (see Arcos et al., 2022, and Wells-Jensen et al., 2022, for exceptions). Learning from the stories of blind and low-vision students and faculty is not only important in and of itself for the unique understandings everyone can gain into seeing and selfhood. Such learning can also help higher education make the shift that Morgan and I call for in an article about one approach to removing barriers for blind and low-vision students: the shift from accommodation culture to equity culture (Cook-Sather & Cook-Sather, 2023). Such a shift, like the shift to Universal Design for Learning principles and practices, would benefit all students and faculty and, more generally, the academic contexts of which they are a part, making those contexts “welcoming and diverse campus environments” (Scott, 2009). Along the way, it would inspire the refinement, mobilization, and employment of the talents and abilities of persons with limited or no eyesight. Shifting from accommodation to

equity culture requires rethinking conceptions of disability, which, many in Critical Disability Studies argue, are what disable, not the conditions of people themselves (Dolmage, 2017; Goodley et al., 2019; Hamraie, 2013).

Numerous blind and low-vision authors have addressed the relationship between seeing and selfhood, a phrase Mintz (2002) coined in her review of Georgina Kleege's *Sight Unseen*. Mintz (2002) suggests that Kleege disrupts the "entrenched connection between seeing and selfhood whereby the blind are constructed as diminished and helpless figures" (p. 155). Equally damaging, however, is the perception of a blind or low-vision person as a "supercrip"—the trope, Kira McCabe (2022) explains, "of a disabled person as an inspirational figure overcoming their disability." One of the problems with this narrative, McCabe (2022) argues, is that "it neglects the challenging systems that come with the disability" and the ways those systems pit people with disabilities against one another in a contrived social game with the underlying assumption, as Nicholas Racheotes notes, "if you've seen one, you've seen them all." These disabling narratives are, as Ray McDermott and Herve Varenne (1995) argued regarding disability in general, "a better display board for the weaknesses of a cultural system" than "an account of real persons" (p. 327).

In *Sight Unseen* and other publications, Kleege writes about how her identity as a woman intersects with her identity as someone with low vision. Other authors have highlighted other intersections and pointed to the danger of when a "single trait" not only "stands in for the whole" but

also “obliterates the whole” (Adrienne Asch, quoted in Leland, 2023, p. 248). In *The Country of the Blind: A Memoir at the End of Sight*, in which he weaves his own lived experience of losing his vision with a far-reaching exploration of blindness, Andrew Leland (2023) builds on Asch’s point to argue that people who are blind and low vision “are dehumanized and oppressed by being reduced to a single, devalued trait”; such reduction does harm to the people being devalued and also deprives the higher education community of a rich dimension of diversity. It may also have the opposite effect of conflating tokenism with the imposed status of role model, adding pressure to what is already an uncertain performance standard. Learning about how multiple dimensions of identity intersect and inform both selfhood and engagement with others is essential to supporting the thriving of those with blindness and low vision and to creating teaching and learning environments in higher education in which everyone can thrive.

Compelled by these authors’ work, sensitized by Morgan’s college experience, and taking higher education as a specific context in which identities are formed and informed, I was inspired to conceptualize this collection of essays by a particular exchange Morgan and I had through which she shared with me an application essay she had written for a leadership position at her college. Morgan has been legally blind since age nine, when she was diagnosed with Stargardt disease, and her sense of selfhood has evolved over time. She included one story of that evolution in her application essay for the position of co-captain of the French Language House on her college

campus (the original French version follows the translation Morgan shared with me):

Ever since I was young, I've wanted to learn French. I began studying it when I was twelve years old in middle school. At that point in my life, the visual impairment with which I was diagnosed rendered me legally blind, and so all of the schoolwork distributed to me had to have bigger fonts. As I grew up, I found that the deterioration of my vision and the continuation of my French studies developed together, thus becoming two big parts of my identity in the present day.

When I was fifteen, I studied abroad in Lyon, France, for three months at an international high school. This experience was one of the best times of my life. However, it was the first time in many years that I felt "blinder" than before. In an unfamiliar place, I had to use visual perception, and I was reminded of the severity of my eye condition when I struggled to see the streets and people around me. Additionally, at the beginning of my trip, I couldn't express myself effectively in French. Little by little, I adapted and found strategies for navigating the city, and with the full French immersion I got by staying with a French host family, I slowly improved my French skills. By discovering my voice in French, it became

clear to me that I loved learning languages, and when I returned to the U.S, I began to study Spanish. I continued with French and Spanish until college, when I chose to spend a semester abroad in Costa Rica, followed by a month-long study abroad in Montpellier, France. During these two experiences, the connection between the state of my vision and language persisted.

Since I was diagnosed when I was nine, until my time spent in Costa Rica, I didn't want to admit or discuss my condition's existence with other people. However, I reinvented my attitude surrounding my visual impairment while in Costa Rica by becoming more open about it and vulnerable. This shift changed my life. Despite my visual challenges, I have decided to leave the country numerous times to seek enhancement of my foreign languages.

I know the chance to study abroad is a privilege, which is why I want to try to recreate these types of experiences that helped me the most, on campus. I am very enthusiastic about the French language and culture. I am the DEI chair of a national honor fraternity on campus, so I have experience planning events and sending reminders. Because I learn slightly differently because of my vision, I am very sensitive to the diverse learning needs of students. If I get this position, I will ensure the students/residents know they can come to

me if they feel an activity is not accessible or effective, because I want to cultivate an environment where everyone feels comfortable and can benefit from the activities.

Original French version:

Depuis que j'étais jeune j'avais envie d'apprendre la langue française. J'ai commencé à l'apprendre quand j'avais douze ans au collège. À cette époque là, la déficience visuelle avec laquelle je suis diagnostiqué me rendait "legally blind" et en conséquence tous les travaux distribués dans mes cours devaient avoir des lettres beaucoup plus grandes. Comme je grandissais, j'avais l'impression que la détérioration de ma vision et la continuation de mes études en français se développaient ensemble et maintenant sont devenues des grandes parties de mon identité.

Quand j'avais quinze ans j'ai étudié à Lyon pendant trois mois au lycée international. Cette expérience était une des meilleures de ma vie, cependant c'était la première fois en quelques années que j'avais le sentiment d'être plus aveugle qu'avant. Dans un lieu inconnu, il fallait utiliser la perception visuelle et je me suis rendue compte de la sévérité de ma situation visuelle quand je ne pouvais pas bien voir les rues et les personnes. De plus, au début de mon voyage, je ne pouvais pas bien m'exprimer en français. Pas à pas

je me suis adaptée et j'ai trouvé les stratégies avec lesquelles je pouvais naviguer en ville. Je suis restée chez une famille française et avec cette immersion complète, doucement, j'ai amélioré mon français. En découvrant ma voix en français, c'était clair que j'adorais les langues et donc quand je suis rentrée aux Etats Unis, j'ai commencé à apprendre l'espagnol. J'ai continué avec ces deux langues jusqu'à l'université où j'ai choisi de passer un semestre au Costa Rica et ensuite à Montpellier. Pendant ces séjours, la connexion persistait entre ma condition visuelle et la langue. Depuis j'étais diagnostiqué avec ma condition quand j'avais neuf ans, jusqu'à mon séjour au Costa Rica, je ne voulais pas l'admettre ni en parler aux autres. Pourtant, j'ai réinventé mon attitude au sujet de ma déficience visuelle au Costa Rica en devenant plus ouverte; vulnérable, et cela a changé ma vie. Malgré ces défis visuels, j'ai choisi de quitter le pays plusieurs fois pour l'opportunité d'améliorer mes langues étrangères.

Je sais que l'opportunité d'aller à l'étranger est un privilège et donc j'aimerais essayer de recréer ces types d'expériences qui m'ont aidé le plus, sur le campus. Je suis hyper enthousiaste de la langue française, et je voudrais maintenir l'atmosphère dans la maison française, qui crée une communauté d'étudiants qui

partagent la passion de la langue et la culture française. Je suis le DEI chair pour une fraternité nationale d'honneur au campus, et donc je sais organiser les événements et envoyer les rappels par email. Aussi la façon dont j'apprends est un peu différente, je suis très sensible aux besoins divers des étudiants. Si je gagne ce poste je vais souligner aux résidents/étudiants que je suis là et quelqu'un peut me contacter s'il pense qu'une activité n'est pas accessible ou effective, parce que je veux que tout le monde soit à l'aise et profite des activités.

Morgan represents her experience—being a dedicated student of French and also being low vision (two dimensions that intersect with others, as she explains in her essay in this volume)—in a different way from how Kleege discusses being female and low vision. These are two of innumerable, unique stories narrated in equally unique ways by those who have experienced blindness and low vision. In addition to highlighting the relationship between seeing and selfhood, Mintz (2002) evokes Michael Bérubé's (2000) argument that “self-representation serves the radical and political function of declaring a self worthy to be named” (p. 155). She affirms Bérubé's claim “that it *does* matter who speaks and that the speaker is a legitimate self” (p. 155, emphasis in the original), and she echoes Bérubé's argument that autobiography “disrupts the kind of dehumanizing ideologies that equate difference with unworthiness, inferiority, and lack” (p. 155).

Shifting Blind Identities in Higher Education: Stories of Selfhood includes the self-representations of five students and five faculty who experience blindness or low vision and who are working or have worked in different higher education contexts. With the first part of the title of this book, I aim to signal several phenomena, all of which inform and are informed by one another:

- With “shifting” as an adjective, I hope those words evoke the ways in which experiences of blindness and low vision shift in relation to other dimensions of identity, depending on context, who is present, and more. This kind of shifting can be positive or negative—the former when those who experience these forms of diversity have the agency to choose which aspects of their identities to foreground for themselves and others; the latter when others make those choices for students and faculty who are blind or visually impaired based on assumptions that are usually deficit oriented.
- Again with “shifting” as an adjective, the first part of the title refers to the changes over time, such as Morgan narrates above, in how people with blindness or low vision experience, represent, and act on the state of their vision and their sense of themselves or their selfhood.
- With “shifting” read as a verb, I hope the title will be understood as a call for a shift in how members of higher education communities conceptualize and respond to blindness and low vision. Rather

than continuing to conceptualize blindness and low vision as only deficits, absences, disabilities, and liabilities to be managed, we can and should shift to conceptualizing blindness and low vision as differences that can require particular contexts, attitudes, and practices to support success and can also inform and enrich everyone's experience of higher education.

All three meanings of shifting here are narrated by the authors' "stories of selfhood"—the subtitle of the book—in ways that reveal their complexities.

The authors of the essays in this collection write from a range of institutional contexts: private liberal arts colleges in Pennsylvania and New York; public research universities in California, Canada, Texas, and Virginia; a public land-grant research university in Oregon; and a public university and an Ivy League research university in Massachusetts. They also write from a range of positions: current undergraduate student; student transitioning from undergraduate to graduate school; current graduate student; graduate student and instructor; graduate student, staff member, and instructor; early-career academic; experienced faculty member; and emeritus faculty member. Their stories are divided into two sections—student stories and faculty stories—and yet nearly all the faculty also include discussion of their experiences as students, affording readers an opportunity to consider how experiences of navigating higher education with blindness or low vision cut and carry across roles. This braiding of diversity

and continuity highlights the intergenerational learning represented and occasioned by the book.

Part I features the stories of five students, both undergraduate and graduate. In “Blink and It’s Gone: Searching for Identity and Security after Sight Loss,” Rose West, a rising third-year undergraduate at Swarthmore College, considers the intersection of anxiety and blindness caused by pediatric brain cancer. She writes about the challenge of accepting her identity because of the traumatic cause of her blindness and the complexities of forging an identity for herself while trying to complicate the identity others impose on her. In “Unfiltered Education,” Ibeth Miranda, a graduate student at Texas State University working on a doctoral degree in Developmental Education with a focus in literacy, explains how her interest arose in studying the use of assistive technology (AT) by students in higher education who have visual disabilities and the influence of AT for making meaning from academic texts. This and other of her research interests have stemmed from her own experiences navigating higher education as a first-generation Latina with a disability.

In “Layers of Identity: Learning to Be All of Me,” Morgan Cook-Sather, a fourth-year undergraduate at College of William & Mary double majoring in kinesiology & health sciences and French & Francophone Studies, writes about how being legally blind as a result of Stargardt disease intersects with her development as student of French/learner of non-native-to-her languages, as a self-re-taught pianist after she lost her central vision and could no longer read

sheet music, as an emerging Diversity, Equity, & Inclusion (DEI) advocate, and as someone with privileged socio-economic status. In “Exploring Our Shared Humanity to Deepen Connections between a Blind and Autistic Student and Her Academic Adviser,” Ashley Neybert, a third-year PhD student in Education with a focus in STEM at Oregon State University, writes about the intersection of blindness, science, and autism. Her essay includes not only her reflections on her selfhood but also a dialogue coauthored with her dissertation adviser Martin Storksdieck that explores similarities and differences between her experiences as a legally blind student and his experiences as a German immigrant in America around code-switching, cultural taxation, and more, modeling for others in higher education ways in which blind students and sighted faculty can work together.

Salaar Khan, a recent graduate of College of William & Mary with a major in government and a soon-to-be graduate student in the University of Virginia School of Law, rounds out the set of student essays with “A Vision for Community.” He writes about how his less visible low vision intersects with his more visible physical disability, how he chose in college to focus on his physical health and well-being, and how communication and empathy are key to creating an inclusive environment.

Part II of the collection features the stories of five faculty. In “Perpetual Transition,” H. May, a professor of theater at Hobart and William Smith Colleges who has retinitis pigmentosa and is also nonbinary, writes about living in liminal spaces in a binary world and choices they have made

around selfhood and self-representation, such as getting a tattoo of a snake on the forearm of the cane-using arm to remind themselves of the power of their fluidity. In “Agency vs. Communion: Why I Have Struggled to Ask for Help When I Needed It,” Kira McCabe, a legally blind faculty member in psychology at Carleton University, considers how her low vision intersects with the psychological constructs of agency and communion and how to balance independence with asking for help. She also writes about the complexity of disability identity and how it changes over time.

In “The View from Here: Insights from a Blind Academic,” RaLynn McGuire, a congenitally legally blind adjunct faculty member who is also completing her PhD in Educational Leadership and Policy Studies at the University of Texas at San Antonio, writes about her struggles with impostor syndrome as well as how she developed a strong commitment to fostering inclusivity, highlighting the dual challenges and opportunities of navigating academia with a disability. In “Adelante: Plugging Through Higher Education,” Karen Arcos, an early-career academic, writes about her experience as a first-generation Latina former University of California President’s Postdoctoral Fellow and former National Science Foundation Graduate Research Fellow who is totally blind, making her a minority in an already small population. She discusses how the community she found with minority undergraduate and graduate students, along with postdocs, influenced her education and career so far. She also suggests what constructs need to change to support success.

With “From the Back of the Mirror,” Nicholas Racheotes, an emeritus professor of history at Framingham State University and research associate at the Davis Center for Russian and Eurasian Studies at Harvard University, writes about navigating denial, “passing” for sighted, and being honest in response to sincere questions, suggestions, and critiques as ways to navigate higher education. He highlights the importance of humanity in higher education—of perceiving others as people.

This collection features student and faculty stories. It does not include stories of those whose primary roles in higher education are that of administrator or staff member. However, some contributors, such as Karen Arcos and RaLynn McGuire, hold multiple roles, including student, staff member, and instructor. The stories are not meant to be representative or exhaustive either of student and faculty stories or of everyone’s experience in higher education. Rather, they aim to expand the number of student and faculty stories available to promote awareness, advocacy, and institutional change. This collection offers a focus on the experiences of a particular subset of those in higher education. It adds depth and breadth to representations of students with blindness or low vision, such as that included in *Enhancing Inclusive Instruction: Student Perspectives and Practical Approaches to Advancing Equity in Higher Education* (Addy et al., 2024), and of faculty, as in *Picture a Professor: Interrupting Biases about Faculty and Increasing Student Learning* (Neuhaus, 2022), which includes a chapter coauthored by blind faculty

members. I hope this collection will inspire other publications that feature a wider variety of differently positioned people in higher education.

These stories of selfhood of faculty and staff share in and contribute to refusing conceptions of blindness and low vision that let a single trait stand in for and obliterate the whole (Asch in Leland, 2023), that dehumanize and oppress (Leland, 2023), and that perpetuate the connection between seeing and selfhood “whereby the blind are constructed as diminished and helpless figures” (Mintz, 2002, p. 155). This is the only collection of which I am aware that focuses on both students and faculty, revealing both cross-cutting themes and differences in their experiences of higher education. It strives to reveal the barriers to developing a sense of belonging in higher education as someone in an academic role with blindness or low vision, a process that includes what Laura Yvonne Bulk (2020) describes as “key nuances such as the importance of interdependence, feeling like a burden, and needing to perform as a disabled person,” as well as various forms of agency and empowerment authors embrace and create. Each story is both situated in a particular present and part of an ongoing unfolding. Each also illustrates a truth articulated by Audre Lorde, who self-identified as a Black, lesbian feminist from an immigrant family and was also legally blind. Lorde (1984) wrote: “There is no such thing as a single-issue struggle because we do not live single-issue lives” (p. 138). For people who live with blindness or low vision, even those with several underrepresented identities, the one that tends to stand out

most to people is blindness. It is incumbent upon all of us not to let a particular form of diversity, often framed only as disability, dominate other identities.

Building on the work of scholars, practitioners, and advocates of “reflexive and politicised Critical Disability Studies” (Goodley et al., 2019, para 6), this collection joins other calls for “barrier-free design” (Hamraie, 2013, para 1) both in literal spaces and in conceptualizations of pathways through higher education. As a sighted person, parent, and educator, I am grateful to have learned and to continue learning with and from these authors and to have the opportunity to extend to readers an invitation to such learning. These authors’ stories of selfhood convey the complex challenges and possibilities of navigating higher education with blindness and low vision and invite us all to honor the particulars of the experiences authors share with us and also to pursue collectively paths to justice (Leland, 2023) and equity culture (Cook-Sather & Cook-Sather, 2023) in our colleges and universities.

REFERENCES

- Addy, T. M., Dube, D., & Mitchell, K. A. (2024). *Enhancing inclusive instruction: Student perspectives and practical approaches for advancing equity in higher education*. Routledge.
- Arcos, K., Jaeggi, S. M., & Grossman, E. D. (2022). Perks of blindness: Enhanced verbal memory span in blind over sighted adults. *Brain Research*, 1789, 147943. <https://doi.org/10.1016/j.brainres.2022.147943>

- Bérubé, Michael. (2000). Autobiography as performative utterance. *American Quarterly*, 52(2), 339–343.
- Bulk, L. Y. (2020). *Being blind and belonging in academia* (T). University of British Columbia. Retrieved from <https://open.library.ubc.ca/collections/ubctheses/24/items/1.0395453>
- Cook-Sather, A., & Cook-Sather, M. (2023). From reporting to removing barriers: Toward transforming accommodation culture into equity culture. *Education Sciences*, 13(6), 611. <https://doi.org/10.3390/educsci13060611>
- Dolmage, J. (2017). *Academic ableism: Disability and higher education*. University of Michigan Press.
- Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, 34(6), 972–997. <https://doi.org/10.1080/09687599.2019.1566889>
- Hamraie, A. (2013). Designing collective access: A feminist disability theory of universal design. *Disability Studies Quarterly*, 33, 4. <https://doi.org/10.18061/dsq.v33i4.3871>
- Leland, A. (2023). *The country of the blind: A memoir at the end of sight*. Penguin Press.
- Lorde, A. (1984). Learning from the 60s. In *Sister outsider: Essays and speeches by Audre Lorde* (pp. 134–144). The Crossing Press.
- McCabe, K. (2022, August 29). Opening your eyes to the burdens of a legally blind professor. Psychonomic Society. Blog post. <https://featuredcontent.psychonomic.org/opening-your-eyes-to-the-burdens-of-a-legally-blind-professor/>
- McDermott, R. & Varenne, H. (1995). Culture as disability. *Anthropology & Education Quarterly*, 26, 324–348.
- Mintz, S. B. (2002). Invisible disability: Georgina Kleege’s “Sight Unseen.” *NWSA Journal*, 14(3), 155–177. <http://www.jstor.org/stable/4316929>

- Neuhaus, J. (Ed.). (2022). *Picture a professor: Intersectional teaching strategies for interrupting biases about faculty and increasing student learning*. West Virginia University Press.
- Sahasrabudhe, S. & Palvia, P. (2013). Academic challenges of blind students and their mitigation strategies. In *Proceedings of the Nineteenth Americas Conference on Information Systems, Chicago, Illinois, August 15-17* (pp. 718-727).
- Scott, R. (2009). *Undergraduate educational experiences: The academic success of college students with blindness and visual impairments*. North Carolina State University.
- Wells-Jensen, S., Michael, E. K. & Mona Minkara, M. (2022). How blind professors win the first day: Setting ourselves up for success. In J. Neuhaus (Ed.), *Picture a professor: Interrupting biases about faculty and increasing student learning*. West Virginia University Press (pp. 33-50).

PART I

STUDENT STORIES
OF SELFHOOD

CHAPTER ONE



BLINK AND IT'S GONE

Searching for Identity and Security after Sight Loss

Rose S. West

INTRODUCTION

My experience with higher education has been confined to the modest two years I've spent at Swarthmore College, a small liberal arts school outside of Philadelphia. With four semesters, sixteen classes, and all but one distribution requirement fulfilled, I'm on course to graduate with my political science degree in May of 2026. I've been fortunate to attend a college

with such a wide variety of opportunities available to me, like getting to interview the incredible disability rights advocate Imani Barbarin, travel to and compete in foreign countries like Mexico with my debate team, and take challenging courses with professors and peers who are deeply passionate and insightful on a variety of subjects. It was the small size promising an intimate and quirky community and the many academic and extracurricular opportunities that drew me to Swarthmore; the fact that it was highly regarded, had a beautiful campus, and was close to home being the final sells.

Admittedly, starting college filled me with that itchy sort of existential dread characteristic of getting older, mixed together with a bone-deep sense of relief to finally be leaving high school behind. Like most incoming freshmen, I saw college as an opportunity to reinvent myself, wanting to fully embrace the beautiful anonymity of no longer being somewhere my reputation preceded me. I quite literally had known a handful of my high school class since we were in diapers, and despite having closer bonds with my teachers than my classmates, I was rather widely known and well-regarded by my peers. It was this very pseudo-popularity I wanted most to escape, and which even now in college I feel the threat of being defined by. After all, I wasn't known for some talent or attractive trait, but because I was the only student who was blind.

My vision impairment is no secret. It wasn't in high school, it isn't in university, and it won't be in my future career. Blindness is simply part of me and will be for the rest

of my life. There is nothing I want more than to be able to declare that fact without any apprehension or shame. And yet, identities are never that clear cut, and my disability has more implications than just an inability to see. My blindness is linked with a deep trauma and intensified by struggles with mental health, making not just being visually impaired, but being visually impaired in higher education, all the more complex.

IDENTIFYING INTERSECTING DIMENSIONS OF IDENTITY

I've always been an anxious person. Maybe it was cute when I was a shy kid hiding behind my parents' legs when meeting strangers, but it was decidedly less so when I started losing sleep and was getting sick over going to school. It grew downright alarming when I would get so panicked that I would lose my ability to think or breathe or calm myself down. I know anxiety isn't anything unique; many college students have it, especially at schools like Swarthmore, which attract a certain flavor of neuroticism. Hell, lots of the general population suffers from anxiety, the relevant statistics only seeming to increase every year. Knowing this, I still feel as though visual impairment further complicates an already overwhelming disorder.

Many common approaches to mitigate anxiety are unwittingly dependent on vision. There are endless centering techniques based on finding colors and naming objects

in an environment, and most reality checks involve actually looking around for reassurance to disprove anxieties. Though similar effects could possibly be replicated through listening or touch, it never is as seamless as a quick glance about. When one then takes the nauseating experience of sensory overload into account, where every slight sound, smell, or physical sensation becomes a persistent stab wound, and when one considers all the visual information being missed in every environment and interaction, it's easy to shut down or explode. All of this is enough reason for someone like me to be on edge, but it doesn't end there. I wasn't born blind, and losing my sight was the greatest trauma of my life.

It happened in 2016. Over a span of six months I began feeling increasingly off. I developed various strange symptoms: a constant heartbeat sound in my ears, vertigo, colorful phosphene spots, stumbling, and frequent migraines. Most notably, my historically typical eyesight began to be harder to focus; letters losing their shapes and being impossible to read while strange patterns formed in blank spaces and objects right in front of me would vanish. I knew that something was wrong, but I was young and lacked the words to make sense of what was happening. I was afraid and grew silent with fear, opting to hide what I was experiencing and playing my symptoms down when anyone noticed. When half my face went numb, I knew I couldn't keep it all to myself anymore, and I was eventually referred to a neurologist. Before I could meet with any specialist, however, I found myself being rushed to the emergency room.

One morning I suddenly lost all the vision in my right eye, and that evening I was diagnosed with a brain tumor.

I don't remember much immediately after my diagnosis. I was dealing with MRIs, an 8-hour brain surgery, heavy painkillers, and dozens of medical staff filtering in and out. It therefore isn't much of a surprise that I can't clearly remember losing the rest of my vision. My neuro-ophthalmologist had initially predicted my sight would improve with time, but, due to unfortunate medical anomalies, it only became worse. The brain is a fragile thing, and the optic nerve is particularly delicate. When subjected to too much pressure, it atrophies, leaving a young girl who once had full vision nearly completely blind. The sight that had been in my left eye had narrowed to all but a tiny pinprick speck of central vision, and without any in my right eye, I am only able to see about 2 percent of what I could before, and which almost everyone else still can.

I am like any other twenty-year-old: I want to feel secure in my identity and discover the person I can become. This self-discovery is often done in college, and it is never easy for anyone, sighted or not. I have been on a journey to rationalize and fully grasp what it means to be a blind student with a brain racked by chemical imbalances and anxiety that never settles down. This intersection of my blindness, anxiety, and trauma seem to contradict one another; the fear and grief I feel over my eyesight seems antithetical to the pride I want to have in my identity. I'm left wondering how to understand and present myself in the center of these contradictions.

CHOOSING AND REPRESENTING EXPERIENCES

Identity is a fickle thing. It is natural to adjust our behaviors and personalities depending on our audience, altering our opinions, speech, and personality based on company context. Past experiences seem the only constant in how an individual acts, the baseline for every value and belief.

Obviously, my cancer and vision loss have been the most defining experiences of my life, but I have this push and pull dynamic when it comes to embracing them. On the one hand, I want to make my struggles feel like they have purpose. In doing so, I've raised funds to fight childhood cancer and become an advocate and a resource for other survivors, having raised thousands of dollars for related charities and actively working with the Children's Brain Tumor Foundation. I've also put substantial energy into learning more about disability civil rights and social perspectives, and I am able to prattle on for hours about the different disability models and on judicial convolutions. My initial interest in my major itself originated with disability, as I wanted to become a better advocate for myself and others. Now I'm considering making it my career. I've also used that passion to try to make social change at Swarthmore, starting a disabled students group, addressing institutional failings, and encouraging disability pride. I use my intersecting identities as a student, a blind young adult, and a brain cancer survivor to fuel my advocacy, and I find so much fulfillment in doing so.

But the anxiety and self-doubt still come.

It's common for students at academically rigorous institutions like Swarthmore to feel inadequate. Being surrounded by a community of intelligent and talented people can easily make you feel like you're lacking, and never feeling good enough seems pretty universal. Being blind is not. Everyone faces endless pressure to do well and fit in, but vision impairment creates an automatic access barrier and social label.

Every assignment takes longer to do, since every assignment is intended to be completed with vision. I find myself relying on extensions and grace for submissions and exams, and I have at least three people working on making my materials accessible at any time, costing my school money and wasting people's time and energy. My peers always seem slightly uncomfortable when interacting with me, like they aren't sure what they're supposed to do. I have to work as hard as possible just to prove that maybe I am redeemable, and assure the world that I'm not a charity case.

If I ever heard any other visually impaired student say these things about themselves, I would immediately intervene. It isn't their fault society wasn't created with their disability in mind, and any accommodations they receive are only "advantages" to the same degree as being able to see may be. They aren't an inconvenience; if anything people are happy to help. If peers are acting uncomfortable that isn't on them, but on their peers for being obtuse and unaware. I'd never tell them the degradations that play inside my own head because

I don't believe that about anyone but myself. It's hypocritical, and deep down I know I shouldn't feel the way I do.

I try to keep my doubt a secret, and present myself the way I want to feel. Fake it until you make it, I suppose. I act comfortable about being blind, always joking and being friendly with strangers so they are more at ease. I'm always willing to answer questions about my disability, and despite the trauma I have from my cancer, I explain it to others like I'm completely unbothered. As I said, I raise funds for childhood cancer and I'm an advocate for those with disabilities, and people admire these traits in me. I bring these interests and experiences into different parts of my life, like approaches to classroom discussions, interactions with others, and engagement with media.

I am well-adjusted on paper, an example of "what can be possible regardless of adversity." In that sense, I fear I often seem like more of an idea, instead of a real approachable person to my peers. I sometimes feel flat, boiled down to only my most basic traits and reduced to an inspirational side character in someone else's story. I've trapped myself in some kind of catch-22 paradox, finding so much value in discussing disability and childhood cancer, but not wanting that to be seen as all I am.

OFFERING HOPES AND INVITATIONS

Higher education is a place of transition. It isn't only where amateurs become professionals, but also where new ideas are revolutionized and formed. Students use college as a chance

to find themselves, meet their people, and explore their passions. Blind and visually impaired students are no different, yet we often have our identities defined for us.

No one wants to admit that they're part of the problem, and oftentimes people don't intend to be. At college, however, I've faced some of the same assumptions I did in high school, and despite being among so many intelligent people, I find that they can be unbelievably ignorant. Often, this ignorance looks like silence.

Sometimes the silence is literal, failing to speak when holding open a door or walking by, forgetting that silence is equivalent to invisibility for the blind. Other times, silence is an absence of what should be said: assumptions made instead of questions asked; being spoken about instead of to. No matter the form, silence is dangerous and exclusionary for the blind and visually impaired, and silence is present on college campuses much more than would be expected for places of transformation and reform.

Another word for this silence is fear. Living my whole life with anxiety, it's pretty easy to see that the discomfort around disability in higher education tends to be from people worrying over saying or doing the wrong things. In a setting such as higher education, especially at colleges where the communities strive to be politically correct and respectful, people are particularly afraid. Questions go unasked in order to not be offensive, but then assumptions are made, and disabled people are avoided to protect from social missteps. Even the most progressive students and staff members at the most progressive colleges and

universities have anxieties about blind people due to how we are divergent from most previously exposed norms, and anxiety is really just a fear of the unknown. Yet, the only way for anything to become known is through exposure, and challenging any discomfort through an active effort to become better.

In the present, the burden largely falls on the blind student. We must make those around us more comfortable with our disability and our existence. When you are only twenty, and are still trying to figure out who you actually are, however, this pressure further complicates our already complex understanding of the self. I am still trying to determine my own relationship with my blindness and how it has shaped me, and must also tend to the impression I am giving off and whether other people are comfortable and perceive me positively. This is extra anxiety I really don't need.

If I could call upon anything, it would be for higher education to break the silences surrounding their students with disabilities. It should not be seen as taboo to create an active dialogue about disabilities such as blindness, especially in a community that is meant to transform young minds and spark social movements.

It isn't going to be easy, but neither is astrophysics. There are really important concerns about respecting visually impaired students and their privacy and comfort levels, but to that I say that this isn't about any one student or any single school. Those in higher education shouldn't only care about blindness when it is relevant to the present moment or

circumstance. Disability isn't just contextual, but it needs to be cultural.

People go to college to learn, find community, and better understand themselves. For me, this looks like a political science major, some friends from clubs and classes, and time to process my identity as someone who has anxiety and happens to be blind due to brain cancer. College should be a place where I can access these goals the same way as anyone else, and not somewhere I must address other people's discomforts and anxieties instead of better addressing my own.

CHAPTER TWO



UNFILTERED EDUCATION

Ibeth Miranda

INTRODUCTION

I am a forever-student, or a student forever...by choice. I choose to learn as much as possible, which will hopefully encompass the rest of my life. Education has always been a priority for me and my family. Without it there are few things one can accomplish in life. And even though not all education requires a classroom on a college campus, mine has led me to higher education as a potential career path. Pursuing a career in education has been my way of ensuring a never-ending pursuit of knowledge and enlightenment for myself as a forever-student and as an educator for my future students.

I self-identify as a blind, first-generation Latina navigating higher education as a student and an educator. I am a child of immigrants, and education was inculcated deep within me as being pivotal for my future. My mother was a single parent, and she did not have the opportunity to pursue her own education, but she always pushed me to be everything that was not possible for her. I have been the first in my immediate family to graduate from high school, attend post-secondary education, graduate with a bachelor's degree, graduate with a master's degree, and currently pursue a doctoral degree. I pursue education for myself and for all those others who cannot for any reason.

Despite my eager pursuit of education, it has not been easy or accessible by any means. I have gradually learned that it takes strong and determined persons with disabilities to take on the great challenge of completing a higher education degree. It is not just the initial challenge of the educational content but getting fair and equitable access to the content itself in the best way for the students' benefit. I was not always blind. My vision loss has been progressive, and with every new level of vision loss, I have had to recalibrate my skills to learn new ways to do old things. Things that I could do visually in the past, I had to learn to do non-visually. I learned to use assistive technology (AT) to access computers and smart-phones through audio means only, and even though AT provides access to most content, it is not easy or truly accessible for all content. There is much work to do to ensure that higher education is truly equitable for persons with disabilities, and

I intend to devote my career to helping bridge that gap for blind students through my pedagogy and research.

IDENTIFYING INTERSECTING DIMENSIONS OF IDENTITY

Even though I love and feel proud of my Mexican American cultural heritage, it can be very oppressive to women, especially a woman with a disability. The pursuit of higher education and academia for someone like me is not typical, and I have had to disengage with traditional cultural and gender roles to pursue my educational goals, even if it means feeling estranged from my own culture. I have mixed feelings about how something as great as education could cause feelings of guilt or loss for the person I did not become.

Despite my mother's unwavering encouragement of my pursuit of higher education, as is typical in our culture, she was also very overprotective and struggled to let me become truly independent because she feared for my safety as a blind woman alone far away from home. Family always tried to "protect" me even if it was at the expense of my own personal growth. At times, I had to disassociate with that culture in order to push myself to break out of my small world at home and strive to be more than it allowed me to be.

My life was nothing like the typical white sitcom TV families I watched on screen talk about their feelings, ideas, and college plans. My single mother was always too busy with

multiple low-paying jobs to have time to discuss anything other than basic needs with me. I do not fault her. She did everything she could to support her children, but the more I learned, the more I felt myself distancing from the life she had worked so hard to allow me to have. It was her hard work that allowed me to have shelter, food, and all the basic things I needed to live a life like those I watched on television or read about at school. Books she would never read. Books I could tell her about one day. I could work instead to help her out. I offered. She would not allow it because she wanted my only focus to be education. She never wanted me to neglect education for any reason. She sacrificed a great part of her own life to allow me to have a better life than hers, and I will forever be grateful for her sacrifice.

That is why I felt guilty that the more I learned, the more distant I felt from my family and everything they expected me to be. The broader my horizons were expanded through education, the more I realized that I did not want a “traditional” life for myself. I wanted to be more than what I had seen a typical Mexican American woman be. I did not want a traditional husband to serve or a litter of children to care for. I wanted to read and write. I wanted my legacy to be my writings not my children. I wanted to speak for myself through my own words and my writing. I did not want others to speak for me anymore. I wanted to stop having my life being filtered through others’ misconceptions of me, which required pursuing a truly unfiltered education.

CHOOSING AND REPRESENTING EXPERIENCES

Physically navigating a college campus with vision loss was difficult, but navigating the hidden curricula surrounding higher education as a first-generation college attendee who is blind, without a parent or an older sibling to guide me through the many nuances of higher education, has been far more difficult. There has been so much to learn about being a “college student,” and whatever exactly that even means, before even adding the layer of blindness to the equation, which I would have to learn on my own. Regardless, it is something that only other college students with their experiences could share, but something that I have figured out on my own through trial and error.

My deep love for education forced me to accept my blindness faster because I just wanted to continue learning however I could. My first educational love was in the field of history. I loved listening to my teachers tell me stories about the past. I was enthralled to learn more about people’s lives and how their actions could lead to great consequences. All my history classes seemed like endless sessions on hot historical gossip! Whatever the deeper reason that attracted me to the field of history, it kept me interested and wanting more enough to complete a bachelor’s and a master’s degree in history.

The history field is reading and writing intensive, and I loved it all! Except when I did not have the actual reading content to learn. Throughout my time in the history field,

I struggled to access the materials that I needed to read for classes. As a blind student, I had to be proactive to search for the reading list as soon as possible to ensure that I could have timely access to the books I would need for classes. It was up to me to reach out to professors months ahead of the start of the semester to ask for the reading.

After introducing myself and explaining my situation, and despite how early it was for them to even finish creating their reading lists, I explained that I needed to know as soon as possible so I could first do my own cursory search to find the texts in a digital or accessible format. If I did not find digital copies, I had to request accessible copies through my school's office of disability services, and if they did not find an accessible copy, then it was time to start manually converting a physical copy either by scanning page by page of multiple hundred-page books or hiring people to audio record the books for me. This process could take several months or more. Despite my actions, many times, I did not receive the books in time to use them for the class or ever. I felt humiliated and like a failure showing up to class unprepared. I had the syllabus and the reading list that let me know when each reading was due, and yet I was unprepared. Not because I did not prepare. I did everything within my power to prepare, and yet in the eyes of my professor and peers, I was not prepared. During these times, I seriously questioned my ability to continue in higher education. There was so much extra labor that I had to perform just to have a chance at getting access to the content I needed, and often all that added labor did not even pay off.

That situation was extremely discouraging for my future outlook in a field I loved so much.

Successful historians write new and unique perspectives on historical events based on primary sources. Even though there may be one overwhelming point of view on a historical event or character, it only takes one newly undiscovered artifact to put a whole new perspective on it. My historical interest was the Mexican colonial period. To be a successful historian, I would have to access primary sources and most likely abroad. Primary sources are often ancient artifacts or texts that are difficult to physically handle and therefore difficult to photograph or manipulate to make them accessible. I could hire an assistant to describe and read for me, but everything I ever knew would be filtered through a stranger's perspective. How could I ever have my own insight or offer my own unique perspective on things without having my own "look" at something? If it had been so difficult to get access to a modern text that should have been simple to convert to an accessible format, how would I get access to artifacts that were so ancient and too delicate to literally handle? I faced many obstacles trying to access primary sources despite explaining my situation. Libraries refused to allow me to scan books or documents that were primary sources because the light from the scanner or the flash from a camera could damage the source. I understand the importance of historical artifacts, but how else would I have access to those sources? This recurring issue became daunting to consider every time I required access to a new source. Would this be the norm for the rest of my career?

Would it ever get easier? Would I ever actually be able to contribute something of unique interest to the field of history if I was so limited in what sources I could access?

A pivot to the field of education seemed to come at the perfect time to recognize my possible contribution to the educational literature. Learning about the diversity of students in post-secondary education through my own experience helped me recognize that I was not alone. The majority of students in higher education have obstacles to overcome. My obstacles have to do with access to educational content. I chose to change my career focus from one focused on a historical perspective to one focused on a future perspective. Instead of studying how things were in the past, I would study how we could change the present to improve the future for students with visual disabilities in higher education. Having a strong foundation of a historical context has been a great advantage to me to help me better understand how to shape the futures of students with visual disabilities. In the field of education, I feel more capable and empowered to contribute a unique perspective because I am living it every day and because I know that I am not the only one. I hope that my experience will help future blind students have an easier path to a meaningful education.

OFFERING HOPES AND INVITATIONS

Readers must understand how inaccessible higher education can be, and how much harder students with visual disabilities

have to work just to keep up with basic tasks. Students who succeed and thrive in higher education do so despite great odds against them and deserve much recognition. It is especially important for me to pursue critical research on how a few of these students succeed and why the majority do not.

My initial exploration of the topic has revealed many gaps in the literature where I hope to contribute my own empirical research. AT can be a powerful tool, but often it is not leveraged to its greatest potential to truly help students with disabilities. There are many modes of AT, but often not enough training with it to reap its benefits. It is also important to understand how different AT modes can be used in conjunction with one another for greater educational impact, or how different AT modes represent the meaning of the content. I look forward to the day when the modes through which we access educational content do not get in the way of actual learning. My mission in life is to help other students with visual disabilities access and shape their own education without the need to have it filtered by others in any way.

CHAPTER THREE



LAYERS OF IDENTITY

Learning to Be All of Me

Morgan Cook-Sather

INTRODUCTION

I am entering my final year of undergraduate study at the College of William & Mary, double majoring in kinesiology & health sciences and French & Francophone Studies. I have served two terms as the Diversity, Equity, & Inclusion (DEI) chair of a national honor society and one term on the Executive Board of the William & Mary chapter of Best Buddies. I have been co-captain of the French House, working

to organize and run daily activities and regular events for students within the French & Francophone Studies department and residents of the special interest housing on William & Mary's campus. I have been on the Dean's List every semester and am on track to graduate summa cum laude.

But there are layers.

It is not until I tell people or they spend time with me that they notice things like that I stop at the top of stairs and take them slowly, clutching the railing, or do not respond when they wave at me across a space on campus. It's not until a professor stands behind me and sees me navigating the zoom feature of my laptop that they even begin to understand what it takes for me to do the work for their class. No one sees the amount of invisible labor that goes into gaining access to course materials, the mental labor of continuing to follow up and advocate for myself when systems are not working for me, or the overall time and energy it takes not only to "keep up" but also to excel.

William & Mary has high academic demands, but I experience the overall culture as upbeat, enthusiastic, and supportive of well-attended showcases of different skills, such as arts and music in addition to sports. Despite the larger size of some of the classes in which I have enrolled, almost all of my professors have taken the time to personally check in on me about how they could best support me in succeeding in the class.

But there are still layers.

In this essay I reflect on several dimensions of my identity—as a student, as a privileged person, as a former athlete—and on experiences of how these dimensions shape my choices: to challenge myself to live in unfamiliar environments and to develop new strategies for playing piano and taking on leadership roles. I conclude with what I wish people would take more care with understanding—the words they use and that vision is on a spectrum—and two of the ways I have actively responded to my eye condition: with developing deeper empathy and with choosing to get tattoos that catalyze deeper understanding.

IDENTIFYING INTERSECTING DIMENSIONS OF IDENTITY

I am a driven student in part because I went to a school that valued my whole being, not just getting good grades, and because my parents were role models and inspirations for high achievement in advanced education but never pressured me or based my value on the grades I earned. Both the academic and home environments I experienced growing up instilled overall confidence in me and gave me intrinsic motivation to engage in my post-secondary studies. I am a successful student because I have worked hard to develop study strategies that are effective for me, and here is where my identity as a driven and successful student intersects with my low vision.

I regularly have to advocate for myself (drawing on my confidence) and explain repeatedly what I need to succeed.

When people look at me, they probably see a privileged white girl who must have no struggles in the world. It's true that my socioeconomic status paired with my ethnicity has given me access to medicine, medical information, and resources, and allowed me to study abroad, afford assistive technology tools, have piano lessons, and more. If people were to look past my appearance, what they would see is that I belong to a community—people with disabilities—who have to constantly navigate misconceptions about us and the physical spaces that are also systems that are inaccessible. My privilege does not protect me from the consequences of those misconceptions and the barriers those spaces and systems create.

I ran track and cross-country in middle and high school with a coach who always balanced being tough, pushing us during practice, and being warm and supportive when I needed it. He sees people's potential and offers guidance that allowed us to realize that potential. My athletic build and belief in myself and in how I can move my body have allowed me to appear to navigate spaces with coordination and grace and mostly without running into things. When people learn about my visual challenges, a common reaction is: "Oh, I didn't know. I couldn't tell."

These different aspects of my identity create a gap between how I experience myself and how people perceive me. I know this is true for everyone, and for me it causes a

tension that makes me feel, on the one hand, as though it is my responsibility to close that gap—to provide an explanation when people get confused about the complexities of having a visual impairment. And yet, on the other hand, I get irritated when people don't close the gap on their own. Because of the insight I have as someone who has a condition that is not immediately apparent and about which others make assumptions, I try not to make assumptions about others. So it frustrates me when others don't respond in the empathic and inclusive way I try to.

CHOOSING AND REPRESENTING EXPERIENCES

I spent my first semester of college studying abroad in Costa Rica through Verto Education. My choice to begin college this way reflects the interest I developed in middle and high school to learn languages and understand other cultures. In my application for the co-captain position of the French House at William & Mary, I wrote: “Since I was diagnosed [with Stargardt disease] when I was nine, until my time spent in Costa Rica, I didn't want to admit or discuss my condition's existence with other people. However, I reinvented my attitude surrounding my visual impairment while in Costa Rica by becoming more open about it and vulnerable. This shift changed my life.” My openness about and comfort with naming my condition informed every situation, from making

new friends to applying for leadership roles. I had already developed confidence in talking with teachers: starting in middle school, I met with my teachers at the beginning of every academic year and explained to them my condition and needs, and I carried that confidence into high school and college. Social and personal relationships were more challenging because of the fear of sticking out during a time—middle and high school—when all I wanted to do was to fit in. But the change I decided on in Costa Rica was essential for communicating in daily ways at William & Mary, such as in the dining hall, about what I needed, and also made sharing that information less of a big deal in communicating with friends.

My growing proficiency in French had a parallel in my developing capacity to openly discuss my visual impairment. At the end of my summer study-abroad experience in France after my sophomore year at William & Mary, I was staying by myself at a small family-owned hotel. One night at dinner, I was taking pictures of the menu, and one of the waiters asked me if I needed an English copy. I explained in my quite-fluent French that I can speak the language but am visually impaired. I share this glimpse of a recurring experience to highlight people's first assumptions and how those intersect with other less immediately obvious aspects of my identity. At that moment I drew on the French-speaking dimension of my identity to articulate another dimension that had not occurred to him but that for me, in the context of being a student and traveler in France, were inextricably connected.

Another language I had learned when I was very young was musical notation. I had taken piano lessons starting at six years old, and until I was diagnosed at nine with my eye condition, I could read sheet music. I quit piano lessons after a couple of years trying to learn piano by memorization, but during the COVID-19 pandemic, I decided to invent a new way for myself to learn piano pieces (I describe this process in my senior project for high school: https://www.youtube.com/watch?v=7h17zFUbk_g). I used the partial music theory knowledge I had learned as a child to create a modified musical language that was accessible to me in order to pursue a practice that was important to me. In college, this practice became therapeutic—during moments of the semester when I was really overwhelmed academically or stressed out, I would go to the music hall and run through my repertoire, and by the end, I felt much more relaxed. The languages I study and the articulation that has been so important to my naming of my experience are strongly auditory for me—an alternative mode of self-expression.

I was fortunate to experience supportive communities for people with visual impairments—particularly Camp Abilities, a sports camp for blind and visually impaired children aged 8–18—which helped me learn to advocate for myself, which is a prerequisite for advocating for others. I brought this commitment to advocacy to William & Mary, seeking the role of DEI chair for my honor society and executive board member for Best Buddies. I realized, through my own experience of being hesitant to be vulnerable and ask for help, that people, once

they know what is going on, really do want to help. This is an issue of education and awareness most of the time, which is why holding leadership positions where I get to bring awareness and an organization's focus to various challenges people face has an impact on how people with and without disabilities experience higher education.

The way I represent myself to others has evolved. Accepting my reality with my vision and, beyond that step, finding ways to do the things that I still want to do have been important. Through that work, I am more OK with who I am and what I deal with. All of that makes me more able to talk to others about my vision condition and experience. For instance, my confidence in my DEI leadership role—the ability to get up and speak to all members of my honor society and tell them I am legally blind—comes from my time studying abroad in Costa Rica during my first semester of college, which allowed me to reset my attitude and my relationship to others. As another example, I made a video with the Studio for Teaching and Learning Innovation at William & Mary about my experience of navigating campus, and that video was shared with the entire college community (you can find it here: https://www.youtube.com/watch?v=7h17zFUbk_g). Taking on leadership roles and making that video forced me to be articulate about my needs and then, more broadly, made me more aware of what I am feeling and convey that to other people. Needing to communicate my condition especially and finding skills to do that, I am also very direct in relationships to say things that need to be said that are hard

to say. I carry that clarity and confidence over into all aspects of my life.

OFFERING HOPES AND INVITATIONS

I would like sighted people to know that you do not get to claim the term “blind” and casually toss it around to describe your daily shortcomings because it is not your identity and you desensitize the word for people who actually have to use it to describe their real-life experiences. Know that I have used the term to literally describe my condition, and because of the way it is used so casually and inaccurately, people have laughed and shrugged off the serious information I was trying to convey.

Having one of those identifiers that people recognize—a cane, a guide dog—must be liberating in the sense that you don’t have to explain yourself, but you still have to prove your capabilities in other ways that are beyond what people assume because you have that indicator. On the other hand, I am someone who in most scenarios passes as sighted, so I experience the other side of the assumptions, where people assume I can do things that I can’t. Either way one plays into society’s expectations. Since being diagnosed with Stargardt disease, I have always felt caught between the extremes of being obviously sighted and obviously blind. I wish people better understood that vision is a spectrum. I can pass because I am in the middle of the spectrum. I feel ambivalent about passing,

though, because the term is typically used to describe fitting in to a mold in a way that negates an aspect of your identity. I wish people could recognize more complexity rather than falling back on either/or assumptions—be open to learning rather than assuming they already know.

Being open to learning both requires and builds empathy. Most people do not, unfortunately, get to a high level of empathy unless they themselves experience something that makes them different in a way that is devalued. The reason I feel that I am empathetic is because I experience a challenge for which I require support from other people and am damaged by the assumptions and societal norms that devalue me. I know what that feels like, so I try to ensure that I am a lot more sensitive to other experiences that might produce that same harm for others.

I have two tattoos—one each to mark milestones in my life of finding my identity. Each was connected to one of my study-abroad experiences—where language, culture, and vision intersect for me and two of the places where I have developed my confidence and capacity to communicate across differences. My tattoos are conversation starters; they open a door for people to hear about what's deeper than the surface, when I explain the meanings behind them. With the realization I had in Costa Rica, the tattoo I got there, which is a dark purple outline of a lotus on my right shoulder blade, is both a reminder of my personal growth and also a commitment to continue to hold myself accountable to stay open, rather than close back up again, and to continue to evolve even more.

CHAPTER FOUR



EXPLORING OUR SHARED HUMANITY TO DEEPEN CONNECTIONS BETWEEN A BLIND AND AUTISTIC STUDENT AND HER ACADEMIC ADVISER

Ashley Neybert and Martin Storksdieck

INTRODUCTION (ASHLEY)

A sense of belonging is important for everyone in schooling, but what do you do when you are automatically othered? As a blind and autistic PhD student in Education focusing on science accessibility, I am sometimes the only blind person

a teacher or classmate has ever met, causing a whirlwind of questions from “How do I teach you?” to “Is it even appropriate to say ‘I’ll see you later?’” There have been many challenges and obstacles that I have experienced in my many years of schooling from not getting accessible materials on time to confusion regarding what does or does not make for an accessible classroom experience.

My instructors often seem confused about the difference between equal and equitable teaching. A teacher might be aiming at creating classrooms based on the concept of equality, where all of the students are treated the same way, even though this could exclude me from participation. For instance, a teacher might require all students to create a graphic organizer in order to represent lessons learned, even though that experience may be inaccessible and confusing to me. In contrast, a teacher might aim at creating an equitable classroom, in which I have an equal opportunity to my peers to complete a task, even if that task might look different for me, such as using the spreadsheet software Excel instead of professional software like SPSS to conduct statistical analyses (with the former being far more accessible to blind students than the latter).

The reason most cited by my instructors for confusing equal with equitable instruction is not being familiar with how to work with a blind student because they haven’t had the experience, leaving them unaware of my needs and potentially confused on how best to ensure that I can participate fully in

ways that accomplish a learning outcome. But what if my experience isn't as different as imagined when going beyond surface features? What if instructors could tap into their own experience of being other or othered to develop more empathy for my situation, which might lower their bar to understanding how best to support me as a learner and student?

This essay explores the similarities and differences between my experience being blind and autistic in science and my PhD adviser, Martin Storksdieck's, experiences as a German immigrant to the United States. We originally took up this compare/contrast approach as a fun thought experiment between the two of us to help take the edge off the extra difficulties that occurred due to my identities throughout my studies. We now coauthor this essay to show that the human experience is often more similar than we are led to believe or might feel inclined to assume.

IDENTIFYING INTERSECTING DIMENSIONS OF IDENTITY

Here we offer more detailed introductions of ourselves.

Ashley: My name is Ashley Neybert. I am legally blind, autistic, and a woman working in the disparity between education as a female-dominated field and the physical sciences often seen as a male-dominated

field. My research interests are in making science more accessible and inclusive for all people with a special focus on sharing my love of science with those with disabilities who have traditionally been overlooked within this space, both inside and outside of the traditional educational environment.

I am used to challenges faced by my identities as I go through school. My undergraduate degree is in chemistry, and I had originally planned to go into chemistry education. However, I encountered an (almost) insurmountable barrier when I learned that at the time there wasn't an accessible version of the American Chemical Society Exam (used as the comprehensive entrance exam in most US institutions). And while there were provisions for "an otherwise agreeable method of proof of subject competency" in the student handbook, my university was worried about standardization over diversification; that is, they were uncomfortable with exam accommodations that, while making the exam accessible to me, might have been seen as lowering their standards for a student. My inability to pass the inaccessible standard exam forced me to drop out of the chemistry program. This was my first highly consequential experience of inequities of the education system.

This experience led me to a deeper analysis of my true goals of making the science I love more accessible to all so others in the future don't face the same barriers I did. As a result, I completed a master's in Curriculum and Instructional Design at Wichita State University and am currently approaching my comprehensive exams as a doctoral student in science education at Oregon State University (OSU).

I am a slightly non-traditional graduate student in that I also work as the Lead Curriculum Designer at Independence Science, a small firm comprised of blind scientists with a mission to expand scientific knowledge through consultation with teachers and the scientific community about inclusive methods that allow blind people a more equitable science experience in school and employment. It was through this work that I originally met my current PhD adviser, Dr. Martin Storksdieck.

Martin: I am part of an OSU STEM Research Center team that is collaborating with Independence Science, Associated Universities Inc. (AUI), and Tumble Media, a small company that created science podcasts for children and youth, on a National Science Foundation-funded project titled STEM Storytelling through Podcasts for Sighted and Blind and Visually

Impaired Students (SSP). The project uses Tumble Media's Science Podcast for Kids as a model of how podcasts can be used in K-12 science classrooms to engage blind and visually impaired students with podcast technology and science storytelling, with broader implications for digital media use in the classroom for all students. As part of the project, Tumble Media will create podcasts that feature blind scientists, as a way to change children's perspective on who can do science.

I came to this intersection with Ashley in a rather circuitous way. I grew up in Southern Germany where I attended the University of Freiburg as a biology student. I first came to the United States in 1987 on a graduate exchange program. Upon finishing my biology degree in 1991, I returned to the United States on a full scholarship to earn a two-year master's in Public Administration, and after that returned to Germany to work in environmental policy. When an unusual opportunity arose in the mid-1990s, I changed careers: I was hired by a German planetarium to write, produce, and present immersive shows on climate change and solar power. In 1998, I moved permanently to the United States, solidified my new career in "informal STEM education" by getting a PhD in

education from a German University, and after working for an independent nonprofit research institute and the US National Academy of Sciences, I became a professor of science education and the director of the STEM Research Center at OSU.

While not directly comparable to Ashley's background, I still carry multiple identities that are part strength and part liability: I crossed three different disciplines by earning graduate degrees in biology, policy, and education; I crossed cultures as an immigrant to the United States, still working across the US and German educational systems; and I straddle between my identity as a scholar and researcher and that of a practitioner. Fortunately for me, I can make productive uses of all three of these identities in my current work.

Ashley and Martin: While our stories seem rather different, in our conversations we realized some pertinent similarities in the intersectional experiences we had. Both of us—Ashley as a blind and autistic person, and Martin as an immigrant and cross-disciplinary scholar—find ourselves in situations where others struggle to understand or appreciate our backgrounds, and where we are the other on an almost daily basis.

CHOOSING AND REPRESENTING EXPERIENCES

So how is immigration similar to blindness? We offer two examples from our thought experiment that highlight key similarities in our experiences. These examples might encourage others to relate to individuals from different backgrounds through enhancing social knowledge of the shared experience of humanity, rather than dwelling on differences.

Ashley: Our thought experiment began with a misunderstanding between me and another professor at my current university. I texted Martin: “I apparently need to figure out how to put more meetings with [professor] in my schedule. [They] asked me where I parked my car on the way out...” We joked about other ways to get around campus—helicopter, self-driving golf cart with sophisticated GPS system—and in the course of our exchange, Martin wrote: “Interestingly, I bike to work so I can more easily get to places on campus if I have to. I think the campus is too spread out.”

We have returned to our comparisons of primary transportation methods on numerous occasions, discussing everything from America’s focus on the car for transportation to the inaccessibility of campus. My university does not have an accessible campus map or an electronic guidance system, and I only know a

basic layout thanks to Martin's willingness to sight-guide me around campus one day for a tour. We have discussed the confusion of the constant construction on campus, and why a beacon system of some form has not been installed to help all students, faculty, and staff better navigate campus. I will admit we are both still learning: I have on more than one occasion received a bike handle to the chest when someone at the STEM Research Center where we work forgets their bike lock and parks the bike at the entrance of the Center as an unexpected barrier that my guide dog cannot protect me from.

Funny how in my life, a bicycle's only purpose is to give me a harsh reminder of the inaccessible transit that is all over our country. For Martin, though, a bike is a way to connect easily across a spread out campus. We made a connection from this apparent difference rather than letting it divide us.

Martin: Another exchange we had was about the similarities we experience around a potential sense of alienation and lack of belonging (Baumeister & Leary, 1995), cultural taxation (Joseph & Hirshfield, 2011), and code-switching (Gardner-Chloros, 2009). I know that being one of just a handful of blind and autistic students at her university triggers constant feelings of otherness for Ashley. I experience otherness

as the constant, if well-meaning, question of where I am (originally) from, triggered by my German accent and people's desire to find connections. In both cases, those who don't know us may be unaware of the cumulative effect of being noted as other, even if the purpose may be to connect or support us. I see a parallel here to "microaggressions" (Sue, 2010), the subtle negative signaling that can occur in the reaction of the environment to a person being perceived as different, though I would not claim that people asking me where I am from really would qualify per se in my case of having a privileged European background.

Cultural taxation is defined as the burden placed on individuals from underrepresented groups to educate others about their culture, experiences, and perspectives, often without appropriate compensation or recognition. Ashley experiences the equivalent of cultural taxation far more than I when she is asked by professors or the university's disability access services how to support her. Each ask of her for help in how to support her might be well-meaning and even needed, but the cumulative burden in time and effort distracts from her academic progress.

The two of us share the experience of constant code-switching in our daily lives. Ashley toggles between reading braille, using screen readers, and

using embossed graphics to access information, and I toggle between English and German in my work and in my private life and between different academic norms between the social and the natural and physical sciences when I collaborate with colleagues from different disciplines. In those three instances we recognize that while our experiences are different in their details, they are similar in concept and allow us to make connections where otherwise we might not see any.

OFFERING HOPES AND INVITATIONS

While not every teacher has experience with blind students, many have had experiences with and training regarding students immigrating from different countries and the additional challenges that students from these backgrounds often face when striving for inclusive experiences in the classroom. We hope that our thought experiment has brought a deeper understanding of how even though the human experience is complicated and full of different individual nuances, it is often possible to find shared experiences as human beings as we all hope for inclusion and strive for a sense of belonging.

Openness and a willingness to learn from one another can go a long way toward the inclusion of a student. This attitude can often make the difference between that student

staying in or leaving a field, place, or organization, and even being encouraged to make changes that enhance and further inclusion and belonging, versus a sense of getting pushed out, driven by the feelings of constant exclusion, an unintentional subliminal messaging that your differences make you unwelcome, and the constant burden of justifying or even having to fight constantly for accommodations that may be legally required.

Instead:

Ashley: The partnership I feel with Martin and our willingness to learn from one another has expanded my personal feelings of belonging in my discipline and my willingness to try and reach beyond perceived limitations from differences found within both myself and my sighted colleagues.

Martin: This new partnership with a blind and autistic colleague and advisee opened the door for critical self-reflection, for gaining new insights about what access, inclusion, and belonging really mean, and for the incredibly sticky and seemingly insurmountable barriers that seem to exist in the physical, institutional, organizational, and cultural world. I had worked in this area of access and inclusion as part of my scholarship and practice, but in joining Ashley's academic journey, I realized far more viscerally what exclusion

still looks like and how much individuals still need to fight to be rightfully present in our institutions.

Ashley and Martin: Most importantly, we learned that our shared humanity is based on finding connections, and in being open to learning about each other with curiosity, empathy, and a growing depth of understanding.

REFERENCES

- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin, 117*(3), 497–529.
- Gardner-Chloros, P. (2009). *Code-switching*. Cambridge University Press.
- Joseph, T. D., & Hirshfield, L. E. (2011). Why don't you get somebody new to do it? Race and cultural taxation in the academy. *Ethnic and Racial Studies, 34*(1), 121–141.
- Sue, D. W. (2010). *Microaggressions in everyday life: Race, gender, and sexual orientation*. John Wiley & Sons Inc.

CHAPTER FIVE



A VISION FOR COMMUNITY

Salaar Khan

INTRODUCTION

Disability has always been a part of my identity, and, in one way or another, it impacts every aspect of my life, including my experience in higher education. In the spring of 2024, I graduated from the College of William & Mary with a degree in government, and as I write this, I am preparing to continue my education by pursuing a JD at the University of Virginia School of Law.

During my time as an undergraduate, I was able to experience personal, academic, and professional growth.

For instance, I used the opportunities of higher education to build on my decade-long commitment to public service both on and off campus. My extracurriculars ranged from helping lead student organizations to advising political candidates to advocating for young people, disabled folks, and communities of color. Outside of my academic and professional work, I enjoy taking care of myself through exercise and nutrition, following my favorite sports teams, listening to music (ranging from new age country to 90s rap), and spending time with my incredible friends. As a whole, all of this can make me seem like a “normal,” if extremely active, young person. And at first glance, most people can’t tell that I am legally blind. But all of these rich parts of my life are tied to my experiences with disability.

In this essay, I hope to relay my own story of intersectional identity to share an optimistic vision from someone who can’t count vision as a strong suit. My story isn’t necessarily unique, but that’s exactly why I hope it can offer accessible insight into not only the challenges folks like me face, but also the simple tools that can help all of us overcome our obstacles.

MY INTERSECTIONAL IDENTITY

I know that to a lot of people, terms like “intersectionality” or even “identity” can seem out of touch, overly academic, or pretentious. However, I am simply using these words to convey how most people feel: there are a lot of complicated

factors that make us who we are. The only difference is that my factors are a little different from the average person's.

I was born with a condition where my legs were different lengths. As a result, I spent my entire childhood combating this problem from wearing shoe lifts to undergoing a series of limb-lengthening surgeries. Instead of running around at recess or playing basketball with my buddies, I was often confined to sitting in a wheelchair or spending time in hospitals. I hoped that this ordeal would be over around the time I turned eighteen, and although I knew there would be effects that lasted a lifetime, I frankly expected some normalcy going forward. But life had other plans.

When I was fourteen years old, I was diagnosed with a degenerative visual impairment that would lead to me becoming legally blind. And even though the concept of disability wasn't new to me, the discovery of my visual impairment produced new obstacles that I hadn't dealt with before. For instance, my leg discrepancy was usually pretty easy for people to spot. If I wasn't in a wheelchair or walking with a crutch, I would still have a large lift in my left shoe and scars from years of procedures across my leg. On the other hand, my low vision is still something people don't often notice without my explanation. I seldom use a white cane, and I've learned how to seem like I'm making eye contact (even if I don't see what I am looking at), so strangers are often puzzled by why I don't drive or why my friends give me a heads up about an upcoming step. The invisibility of my impairment puts it squarely on me to disclose my visual limitations to new people.

Moreover, my low vision diagnosis added new layers to the accommodations I needed to interact in the world around me. Although I sometimes struggled within the confines of my leg discrepancy, the changes I needed to make were largely solitary. I might have needed a lift in my shoe or to leave class early to wheel myself to the next period, but I could still be relatively independent within these confines. On the other hand, my poor vision meant that I needed to explicitly ask others for help, whether it was asking teachers and professors for a digital copy of a paper handout or asking a friend to read me a menu at a restaurant. Initially, I was uncomfortable in these conditions. I tried to do things by myself without burdening instructors or peers, and the results were reduced performance and increased stress. I realized that collaboration and honesty would be crucial assets for me to thrive and help others do the same. After all, if I could not pull my own weight, it would be difficult for me to truly contribute as a student, friend, or community member.

TOOLS TO OVERCOME ADVERSITY

In the last decade, my experiences have not only taught me to endure the problems created by my limitations, they have also revealed solutions with useful application outside the strict context of disability. These include both steps I have taken to work on myself as an individual, as well as skills I have developed to help me interact with the world.

After hearing about my physical disabilities, you won't be shocked to learn that I was not a star athlete in my adolescence. In fact, I often felt physically limited by my intersecting disabilities, and for years, I let myself be a captive to this excuse. Of course, there are physical limitations that are simply a reality of certain disabilities. But during my time in college, I realized that these restrictions do not prevent me from being a healthy and active individual. In the last few years, I have transformed my lifestyle to prioritize my health from following a rigorous exercise regime to making informed and thoughtful choices about my nutrition. These changes have improved my confidence, strength, endurance, and mental health. And although neither lifting weights nor eating enough antioxidants can fix my leg or restore my vision, taking initiative in relation to my own health has challenged the notion that I am shackled by my physical limitations.

In addition to the utilization of my physical health to reduce the impact of my disabilities, I also learned to advocate for myself to directly address these issues. I am proud of who I am, but for years I clung to the ridiculous notion that it would be embarrassing to admit that I can't see. And as I previously mentioned, I wanted to be independent, which, at the time, I thought meant figuring out my accommodations on my own. But eventually, I learned that my silence was helping nobody. Even if a teacher was supposed to know the accommodations I needed, it was only human nature to forget. So when I failed to speak up, I put both myself as a

student and my instructor in an unenviable position. At first, it was admittedly stressful to make the long walk from my seat to a teacher's desk in the midst of a dead silent classroom taking a test to speak up for myself. But this kind of communication was crucial to getting the help I needed. Over time, I was able to easily tell people that I was legally blind and communicate what I needed in a way that put them at ease. I used jokes to highlight my positive attitude about the situation, and I opened myself up to questions. All of this helped people feel comfortable with me and my vision, and it helped create a mutual dialogue for open communication that empowers me to share my needs and address others' concerns. I have found these kinds of tactics helpful in all kinds of settings from higher education to workplaces to new social settings. A smile, a friendly explanation, and a few jokes can go a long way toward accomplishing much more serious goals.

But none of my work on myself for my own health or relationship with others would have been enough without the support of the people around me. During my life, there have been countless teachers, counselors, friends, and others who have taken actions, big and small, to make my life easier. I genuinely believe that most people want and are willing to help others, and my community is a proud manifestation of that faith. Of course, the people around me still make mistakes or forget about my impairments, but again, this is why honest communication matters. When I was able to share how others might be able to lend me a hand, I found amazing people in all parts of my life who have gone out of their way to do so.

Taken together, all of these methods I have used to overcome my obstacles help shape who I am. When I examine my identity, I know it would be foolish to ignore my disabilities, but I am not just defined by the problems I face; I am defined by how I solve them. Although I usually hate clichés (almost as much as I dislike the Green Bay Packers), I am reminded of the popular quote from former Packers coach Vince Lombardi: “It’s not whether you get knocked down; it’s whether you get up.”

Like a lot of folks facing adversity, I have to work harder, think faster, and be kinder to achieve my goals. I often encounter setbacks, but it is how I “get back up” that makes me the man I am. My personal drive makes me more ambitious, my focus on honest communication makes me more empathetic, and my gratitude for others is the basis for my dedication to service. Without these skills, I would not be a successful student, positive friend, or a trusted leader in my community. Thus, my response to my disabilities, rather than the disabilities alone, define my identity.

WHAT I HOPE

I hope that people will understand that the everyday problems of low vision are complicated. Especially in a competitive environment like higher education, student performance matters, and the inconveniences of visual impairment can interfere with these results. Thus, I hope that readers will listen to blind people’s needs, not with skepticism, but with

empathy. I've personally had administrators who approached my requests with doubt and made me feel like a burden for the help I needed. This approach only discourages disabled folks from succeeding and limits people's potential.

But just as the difficult nature of visual impairment makes it important to listen to blind people, I also want readers to know that accommodations are not a definitive answer. There are constant issues that can arise in higher ed, from a well-meaning professor who forgets to say my name when they call on me in class to an unreadable dining hall menu, that are more numerous and nuanced than any formalized accommodations can address. This is exactly why I put so much stress on honesty and empathy. I hope people will try to address visual impairment in higher education through open communication with and understanding for one another.

For instance, when problems inevitably come up, faculty and classmates should try to understand the struggles of their impaired peer. I encourage them to listen, ask questions, and help when they can. On the other hand, my blind friends have their own responsibilities. They should advocate for themselves, even when conditions are hard, because nobody can communicate for you better than you yourself. Moreover, I encourage them to be patient and understanding when people around them make mistakes or do not understand their abilities. I know folks with all kinds of disabilities who can get understandably frustrated by others' ignorance, but the best way to combat this lack of knowledge is not anger. Instead, I hope they will take the steps to choose empathy and honesty.

More than any other takeaway, I hope that people approach these situations with a positive attitude and try to build collaborative communities. Having a positive attitude and taking initiative are valuable practices for people both with and without visual impairments. For a blind person like me, it has enabled me to take ownership of my own limitations, actively solve my problems, and see the best in others (metaphorically speaking, of course). For my counterparts without these impairments, the same attitude better equips them to work with others, including folks who may need help, and to ask for help themselves. And if each person in higher education has a better approach to making themselves and the people around them better, it will create a culture where people of all abilities and backgrounds can work together.

In this specific essay, I was able to use my own story of blindness and disability to make the point, but it is frankly universal. Everyone has their own challenges or problems. Everyone needs help from time to time, so we can all benefit from a community that supports one another. I hope that my insights and advice can empower more people to create these kinds of communities in higher education and beyond.

PART II

FACULTY STORIES
OF SELFHOOD

CHAPTER SIX



PERPETUAL TRANSITION

H. May

I am
still liminal
always in transition
hidden in plain sight—theirs, not mine
awake

What does it mean to be blind? When I was in the first years of my teaching career, I was confident I knew the answer. Blind people used white canes, saw nothing but darkness, and were unable to fully engage in everyday life. (I now

know that only a small number of blind people see absolute darkness, some blind people use canes, and all blind people are fully capable of living rich and complex lives.) At least, that's what I assumed when a student showed up in my directing class using their white cane. I wish I remembered their name so I could apologize for my inability to provide them (and their sighted peers) with a multi-sensory classroom experience.¹ I never questioned the fact that I could not drive in to campus without my contacts but assumed myself sighted.

Today I find myself wondering just what the difference is. Why does only one of these assistive devices cause someone to be perceived as blind? And more to my own chagrin and shame, why do I continue to cater to negative perceptions of blindness and generally avoid using my cane...even though I know it allows me to move with confidence?

UNSTABLE FOOTING

A little over a decade ago, I took what I imagined to be my last academic position. Hired as an Associate Professor (without tenure), I felt like I already had a good sense of who I am professionally and personally. I thought I had arrived at my final destination—literally and metaphorically. Shaped by a culture in the United States that defines people by their occupations, successes, and fixed notions of identity, I imagined this final (long) chapter as one that would

simply empower and reaffirm my sense of self. I was in for a rude awakening.

Immediately upon my hire, colleagues began grilling me about whether I thought I could successfully achieve tenure. Given that I had previously earned tenure at Auburn University and agreed to give it up to take my job at Hobart and William Smith Colleges (HWS / The Colleges), the question startled me. What did my colleagues know that I did not? It turns out their questions had little to do with how they valued my work and everything to do with the way the institution demands that those living and working here identify themselves as worthy of support. Initially I imagined my unstable footing on campus had to do with my precariousness, but it didn't abate after I was unanimously awarded tenure.²

Although I couldn't have articulated it then, I arrived on campus a blind(ish) nonbinary genderqueer at an institution with metaphorical and physical structures that deny the existence of these lived experiences. (I find all language about identity slippery. How I know myself is always situational, deeply influenced by power and privilege, and evolving—both in terms of the wider culture and also in terms of selfhood.)³ The President's, Provost's, and Diversity, Equity, and Inclusion offices are in an old building with many stairs, no elevator, limited handrails, a dark wooden interior, and dim lighting (HR was also in this building for many years). The facade and front stairs serve as the backdrop for commencement and endless photo ops.⁴ These spaces are nearly impossible to navigate without full vision and are impassable for

anyone unable to climb or descend stairs. As the seat of power and public image, they send a clear signal as to who belongs on our campus.

SYMBOLIC EXCLUSION

Hobart and William Smith Colleges is one of a handful of remaining coordinate college systems in the United States. The name of the institution represents two distinct colleges divided by gender but placed in dialogue with each other. (Academically, classes are open to students from both colleges.) Through the naming of the institution, nonbinary individuals at HWS are erased from existence in the public imagination, even as we live in its embodied reality. While I did not identify as nonbinary when I began employment at HWS, the binary imagination of gender enacted every day on this campus forced me to recognize that I am alienated by this system. A variety of circumstances⁵ in my first year at The Colleges awakened me to the harm caused by HWS's continued commitment to coordinate college education.⁶

Although the coordinate system was described during my campus interview as having no impact on faculty life and a minimal impact on students, experience shows otherwise. I continue to advocate with students, faculty, and staff for the abandonment of the system. Repeated discussions with alumni and administrators, however, reveal deep resistance to its full elimination, especially in name.⁷ While my nonbinary

students have largely found ways to successfully navigate this violation of their identities (typically by focusing on the material benefits that a degree from HWS will bestow upon them and developing strong peer networks), I find myself increasingly agitated by the institution's investment in a way of organizing and understanding the world that by definition denies nonbinary existence.

PHYSICAL / EMBODIED EXCLUSION

Four years into my employment at HWS, I went to the ophthalmologist because I had literally run into large items (a stone bolder and a fallen tree). A barrage of tests revealed parts of an identity I already understood from lived experience but did not know to claim: a genetic disorder that causes progressive blindness. As someone who grew up steeped in a culture that uses the medical model to understand disability, it wasn't until I received a diagnosis that I began to recognize I needed new ways of working.

Although my lived experience hadn't changed with the diagnosis, my understanding of my identity did. I wondered how I would continue to work as a blind person in fields steeped in ocularcentrism (theater and higher ed). Lacking role models, I made an appointment to talk with my Provost about my options. After abruptly ending our first meeting and asking me to reschedule, she started our second meeting by asking if she could pray with me. I didn't know how to say

no. Shortly thereafter she ended the meeting with an offer to drive me to appointments but provided no clarity as to the process by which to request accommodations. I went to her in her role as the administrator tasked with overseeing faculty concerns, not as a potential friend or aid provider.

In neoliberal settings, the struggle to create equitable and transparent processes and procedures that address the social constructs and structures that disable people is replaced by an understanding of disability as an individual medical condition to be treated with “accommodations.” (I use scare quotes around the word “accommodations” because of both the deficit model implicit in this idea—as though a disabled approach never has anything to offer abled individuals—and the way it ensures that normative / ableist structures remain intact.)

The only office on campus clearly addressing disabilities is for students. At the time I learned about my disability, there wasn’t even an online resource for faculty accommodations. Instead, faculty and staff were expected to know whom and how to ask. The clarity of this process has improved, but only after sustained activism and pressure from a group of faculty with disabilities. Many of these faculty members have subsequently left academe, died, or stopped organizing after they became exhausted and disillusioned by the process. Without engaged collaborators and with my gained knowledge that few advancements have been achieved through our activism, I, too, have largely abandoned this fight.

In my experience, faculty are forced to expend an inordinate amount of time and labor working to obtain individual

accommodations, thereby ensuring that we do not have the time or energy to collectivize and push for systemic transformation. Furthermore, when someone does push for systemic transformation, they run the risk of either being publicly outed as disabled, feeling like they have to publicly out themselves to help abled colleagues understand the realities of the situation, or, in my case at least, both. In an ableist institution, being recognizably disabled carries risk. Years into a seemingly endless process of telling my story, I have grown weary of it.

WHAT I WISH SOMEONE HAD TOLD ME

I joined the ranks of the disabled relatively late in life and my career. I arrived weighed down by all of the ableist baggage in our culture, and I was ill-prepared for the moment. With the acknowledgment that all institutions are different, here are the most significant things I wish someone had told me:

- You will be asked to provide specific suggestions for all accommodations such as equipment / software purchases. Knowing what to ask for is hard when you are newly diagnosed and not yet connected to others with your disability.
- Although your institution will demand that you provide precise suggestions for accommodations, it will also question your decisions and ask repeatedly for medical documentation validating your choices. This will eat up valuable time.

- Medical documentation will prove difficult and sometimes costly to obtain.
- Although you have a degenerative disability, you will repeatedly be asked for documentation, even when you are requesting the same accommodation you used in the past.
- Higher ed administrators turn over frequently and each new hire will require you to repeat steps of this process.
- You would usually be better served to imagine your own solutions or rely on mutual aid than to work with your HR department.
- While you may want to address ableist barriers on an institutional level, the institution will force you to simply focus on your own requirements.
- Tenure and promotion guidelines are not created with disabled faculty in mind.
- Disability, like all of identity, is situational and always evolving.

ALWAYS ALREADY IN TRANSITION

Last summer, at the age of fifty-three, I got my first tattoo. It's a means of reminding myself and others about the infinite transformations we undergo in life. It's an odd choice, to be sure—permanently inking my skin as a means of embodying the transformation I feel every day—but somehow transition

is the one thing that feels eternally true. We are never in our final form.

My tattoo is a colorful snake that covers my entire forearm. The scales on the lower body transform to greyscale in a process of molting. I chose a snake to honor Tiresias, the figure from Greek mythology who was cursed by the gods to shift genders after striking and killing a pair of mating snakes. Like Tiresias's, I imagine my snake as a source of multi-gendered knowledge. As a petite white person, I am nearly always identified by strangers (and people I know) as a fragile woman. Even without my cane, aging brings an additional association with dependency, as demonstrated by the frequency with which office staff refer to me in infantilizing terms like "dearie." I hoped that tattooing a fierce snake on my arm might challenge this perception. (Unfortunately, cultural norms are much stronger than a tattoo.⁸)

My snake is also for me. Tiresias was cursed with blindness by the gods, then given the gift of insight to make up for it.⁹ They appear in multiple Greek tragedies, offering prophecies to the heroes who summon them. Those heroes inevitably disregard Tiresias's insights and then suffer the consequences. Because Tiresias knows they are more likely to be blamed than listened to, they are wary of speaking. In the end, however, they refuse to hide the truth. I admire Tiresias's righteous anger and unwillingness to be shamed for blindness. My snake adorns my right arm, the arm that I use—on occasion—for my white cane named Cassandra, after another Greek prophet who spoke the truth but was generally ignored. I know she

can see my future, but only if I listen to her. My snake tattoo encourages me to do so, to fiercely refuse to be shamed for using a cane and embrace and make visible my blindness to others.

NOTES

- 1 I assumed the blind student could only engage with theater on an auditory basis and offered them the opportunity to direct a radio drama instead of a fully staged scene. They told me they wanted to do the same assignments as the rest of class. Relieved, I made no changes to the way I taught the class or assigned materials. I now incorporate assignments of radio drama and audio description alongside standard blocking exercises, recognizing that all of my students benefit from approaching the theater in a multi-sensory way.
- 2 In my second decade at HWS, I am now a full professor with an endowed professorship.
- 3 At the time of writing this essay, I most frequently refer to myself as blind(ish) because I still navigate the world primarily in the way a sighted individual does. I have not yet made the time or found the resources to learn the techniques of most adaptive technologies, nor have I fully embraced using my cane. I hope to make time for these things during my upcoming sabbatical. Furthermore, I have never been diagnosed officially as legally blind, which means that outside organizations do not recognize me within that category. I use genderqueer and nonbinary because I feel a productively disruptive lack of identification with the gender binary.

- 4 These issues are also prevalent in theater department spaces. While our mainstage theater and some of the affiliated areas (like dressing rooms) are accessible, the only discipline-specific classroom space (and most storage) is on the second floor of an old building that also lacks an elevator.
- 5 These circumstances include: participating in a trans studies reading group facilitated by a trans colleague; founding a social justice theater company and collaborating with a student who came out as trans (this student is one of many subsequent trans students who have taught me how to rethink my own relationship to gender); working with a group of trans students and allies to hold a teach-in on campus; reading “Hobart” or “William Smith” next to every name on class rosters; and hearing faculty consistently attribute low levels of scholarly achievement to male students by articulating it as part of the Hobart experience.
- 6 Probably the best way to understand HWS’s coordinate history and present is to search The Colleges’ website. At the time of this writing, the last statement was issued by the President and Board of Trustees in 2019, when they affirmed a “commitment to the coordinate heritage and mission” with a goal to “evolve the coordinate construct to be more inclusive” (McGuire, 2019).
- 7 HWS has made some changes such as offering joint degrees, the ability to choose which college students affiliate with at any point in their relationship with the institution, and some merging of ceremonies.
- 8 Even when I wear a T-shirt that reads “Just a They / Them out causing May / hem,” I am typically referred to by she / her pronouns.
- 9 Blindness, and not gender transformation, is the curse that most theater people know Tiresias received.

REFERENCE

McGuire, P. A. (2019). Email to HWS community later uploaded to the HWS web page for “Coordinate Tradition Resources” under “Past Statements: April 27, 2019.” Hobart and William Smith Colleges. Retrieved May 23, 2024, from <https://www.hws.edu/about/history/coordinate-tradition/resources.aspx>

CHAPTER SEVEN



AGENCY VS. COMMUNION

*Why I Have Struggled to Ask
for Help When I Needed It*

Kira O. McCabe

INTRODUCTION

As someone who grew up in the southern United States, I never would have expected the life trajectory that I've had so far. I've been fortunate to travel the world for my education—first attending universities in the southern United States: Oglethorpe University in Atlanta, Georgia, for my BA in psychology, and Wake Forest University in Winston-Salem,

North Carolina, for my MA. I then lived outside the United States for seven years. I lived in the Netherlands for four years while working on my PhD at the University of Groningen. Then, I lived in Australia (Perth and the Gold Coast) while working as a postdoctoral fellow. I moved to Nashville, Tennessee, for a second postdoctoral fellowship at Vanderbilt University. Now, I am Assistant Professor of Psychology at Carleton University in Ottawa, Canada. As someone who had a difficult transition moving from my hometown of Charleston, South Carolina, when I was almost ten years old, I certainly have moved more than any other member of my family.

Given all these moves, people are often surprised to hear that I have a visual disability. I was diagnosed with Stargardt disease when I was thirteen. Not as much information was available then as it is now, and there were general concerns that I would be completely blind before I reached adulthood. After a period of adjustment, on which I will elaborate in my essay, I was determined not to let my disability interfere with my goals. I was smart and did well in school. And while my parents do not hold college degrees, they encouraged me to do well in school and to go to college. I was a bit naive about how hard the path I chose would be, but I was rather stubborn about pursuing my goals.

When looking at these outcomes, people may reflect on the success that I've had to "overcome my disability." This puts me in an awkward position for several reasons. It falls into the "super crip" trope, in which people are inspired by

my story and blame others with similar disabilities for not being more like me (McCabe, 2022). It also masks the ableism and challenges that I have faced along the way. Some of these challenges are internal—struggling with my disability identity and personal values. Being disabled means that sometimes you need to ask for help. But when internalized cultural values emphasize independent living and self-sufficiency, what should you do?

IDENTIFYING INTERSECTING DIMENSIONS OF IDENTITY

In many western societies, parents raise their children so they can be thriving adults who live and work on their own. We have many phrases for this value: self-sufficiency, independent living, personal agency, rugged individualism, and so on. We laud people who pull themselves up by their bootstraps to prosper later in life. We like to take pride in our personal accomplishments and independent work. Yet how does disability fit with these western values?

When I was a child, I was quite independent. I was shy to strangers, but among family and friends, I was quite assertive. I would do things on my own. An often-cited example was when I was seven, I found out that classmates were receiving more money from the tooth fairy than I did. When I lost my next tooth, I wrote a letter to the tooth fairy asking for a raise. I put it under my pillow with my tooth—without telling

my parents. When I was diagnosed with Stargardt disease at thirteen, I struggled to adjust to my diagnosis. In school, I was reluctant to ask for help. I was an independent person after all, and I didn't want to bother others. This issue came up at a parent-teacher conference, and my mother regularly reminded me that others wouldn't know if I needed help unless I said something. I had to learn to advocate for myself—even to strangers. I couldn't always do things alone anymore.

Why do some people with disabilities struggle to ask for help? In part, it reflects tension in these values of agency and communion (Bakan, 1966). Agency includes striving for individual accomplishments, mastery, status, power, and control (McAdams et al., 1996; Wiggins, 1991). Communion, by contrast, includes prioritizing other people and the broader community (McAdams et al., 1996). It includes striving for love, friendship, and helping other people. These values are separate concepts, so you can be high or low in both values (or somewhere in between).

Given the emphasis on agency in western cultures, disabled people may struggle to ask for help, even though they have a needed accommodation for school or work. We don't want to draw attention to the fact that we can't always do things on our own. Beyond internalized values, this issue also comes up in the stigma of asking for disability support. Are you disabled enough? We often jump through hoops to get accommodations and prove that we need them. Both the internalized and societal agency values make the simple act of asking for help a challenge.

Communion values and disability are also complex. I have many wonderful, supportive friends and family around the world. Yet I don't want to be a burden on them by asking them too much for help. If a friend offers me a ride home, I almost always ask, "Are you sure? I don't want you to go out of your way." I don't want my relationships with others to become transactional. My friends generally have no problem with this—it is just more of my internal conflict of being disabled and being self-sufficient.

I've been managing my disability for over twenty-five years, and I still sometimes struggle with these issues. I often downplayed the effects of my disability in graduate school. Later, I just opted not to discuss my limitations unless explicitly asked about them. I didn't have it as bad as others, so why should I draw attention to my problems? Accepting that you have a disability is one thing; incorporating disability into your identity is another.

CHOOSING AND REPRESENTING EXPERIENCES

In the last twenty-five years, I have learned to balance my agency and communion values despite my disability. I have lived and traveled all over the world, which was something I had not planned to do when I started studying psychology. However, I was determined not to let my disability hold me back from great opportunities. When learning to live in a new country, you almost always need others to help you. When

I first moved to the Netherlands for my doctoral studies, I was consistently learning things just to get by in everyday living—about which my Dutch friends were great at giving me advice or teaching me the Dutch systems to things. This expat experience is quite common whether you have a disability or not. Disability is adjusting to a new way of doing things, and living abroad is an extreme version of that kind of experience. Yet in some ways, I was more self-sufficient with my disability in the Netherlands than the United States, given the excellent Dutch public transportation and cycling network. But I still needed help and guidance from my Dutch friends to adjust to living in a place so far from the support of family and friends back home. I needed agency and communion to thrive in this time.

In my time abroad, I completed my doctoral degree and postdoctoral studies. These are personal accomplishments that are common examples of agency. However, I did not do this alone. We may like to tell ourselves the myth that we are responsible for our personal achievements, but this is rarely the entire reality—whether you have a disability or not. We do a lot of hard work, but we also need other people to support us in the process of completing our degrees.

During my doctoral studies, I became more accepting of my own limitations. When I experienced eye strain, I needed to give myself time to rest. If I couldn't read or do as much as others because of my disability, then I would adjust my deadlines accordingly. At the same time, I would help my

fellow Dutch graduate students, too. We all wrote articles in English for our work. For native English speakers, we don't think about this issue at all. But for fellow Dutch students, they wrote in their second (or third) language. People would often drop by my office to ask me a quick grammar question as they were working as I was a native English speaker. We all could use help on the path to complete our doctorates. Asking for help should be a normal thing, and it shouldn't take away from the things that we are able to accomplish.

My international travel and graduate work helped me to grow in many ways. I balanced my agency and communion values, and I also became better at talking about my disability. I am disabled. I can't do everything because of it, and I need help sometimes. We all need help at times, for many reasons beyond whether we have a disability or not. I learned to speak up about how to make things more accessible for people with visual disabilities. I have helped some of my professional conferences promote accessibility guidelines to make things easier to read. I will give feedback to colleagues who ask how to help their students with visual disabilities. I reviewed statistical software to figure out what accessibility features work well and where there can be improvement. Rather than placing the burden on others with visual disabilities to ask for help, I try to speak up for them and let people know of how things can be better. This is especially important for students who don't have as much power as I do to be assertive and push for change. And in many cases, these accommodations not only

help people with visual disabilities, but they also help everyone read and see things better.

OFFERING HOPES AND INVITATIONS

I hope that readers embrace the complexities of disability identity. It can impact everything in our lives—from how we plan our careers to what we want to ask of our family and friends.

For those with visual disabilities, it can be hard to ask for help. As we live in a society that promotes self-sufficiency, disabled people learn that they can't always do everything alone. We may struggle to ask for help. Part of this struggle is tied to our values of agency, but it is also related to our values of communion. We don't want to burden our friends and family. For people with disabilities who read this—please understand that this is normal and try to give yourselves some grace. Advocating for yourself is challenging and it can be exhausting. Incorporating your disability into your overall identity can take time, too. It is important to understand that we all have our own path, and there is no “right” way to manage things.

For those without disabilities, I hope they can gain some insights, too. Don't assume people with a disability need help unless they ask for it. Yes, it can sometimes be hard for us to ask for help, but it doesn't mean that you should jump in and do things for us either. Offer to help first. Give us the option and the agency to elect for help if we need it. More times than not, we have systems in place that you might not know to

accommodate for our disability. It is important to listen to what people with disabilities need.

At a broader level, I hope that we are more comfortable with providing support for people with disabilities to thrive in society. People with disabilities are often underemployed, and this is typically due to an underlying assumption that people have about disabilities. One time, a medical doctor asked me if I ever took a disability check. I replied that I had not—that I had always worked. He replied, “Good for you.” I had no idea how to respond to this. I was angered by his assumption, and I was also angry as I considered his attitude if I had replied that I had. The truth is that managing a disability is expensive in many ways. But we shouldn’t be dismissive of those who need financial support. Nor should we dismiss the potential for people with disabilities to contribute to society if we had the supports in place to thrive. As noted above, we rarely succeed alone. Increasing tolerance in society to support people with disabilities is incredibly important for all of us to flourish.

REFERENCES

- Bakan, D. (1966). *The duality of human existence: An essay on psychology and religion*. Rand McNally.
- McAdams, D. P., Hoffman, B. J., Day, R., & Mansfield, E. D. (1996). Themes of agency and communion in significant autobiographical scenes. *Journal of Personality*, 64(2), 339–377. <https://doi.org/10.1111/j.1467-6494.1996.tb00514.x>

- McCabe, K. O. (2022, August 29). Opening your eyes to the burdens of a legally blind professor. *Psychonomic Society*. <https://featured-content.psychonomic.org/opening-your-eyes-to-the-burdens-of-a-legally-blind-professor/>
- Wiggins, J. S. (1991). Agency and communion as conceptual coordinates for the understanding and measurement of interpersonal behavior. In D. Cicchetti & W. M. Grove (Eds.), *Thinking clearly about psychology: Essays in honor of Paul E. Meehl, Vol. 1. Matters of public interest; Vol. 2. Personality and psychopathology* (pp. 89–113). University of Minnesota Press.

CHAPTER EIGHT



THE VIEW FROM HERE

Insights from a Blind Academic

RaLynn McGuire

INTRODUCTION

My childhood bedroom was my first classroom. I can still remember my six-year-old self, wearing my favorite purple dress, standing at the foot of my bed teaching my most promising pupils—my favorite stuffed animals and Cabbage Patch dolls. I don't remember not knowing that I wanted to be an educator. When I think about who I am as a person, educator is one of the core ways I see myself. However, there are other ways that I identify that cause tension and beauty to coexist.

School was the first place that made it clear to me that I'm disabled. While I knew that my eyes didn't work the same as everyone else's, my parents and family made me believe that I could do everything my peers could do. But I have a rare, congenital eye condition called coloboma. I have some functional vision, but I've always been legally blind. As a result, engaging with print, seeing the board or PowerPoint presentations (yes, even from the front row), and accessing a computer are all things I cannot do without assistive technology. My deep love of teaching and learning is contrasted by the sheer amount of effort I had to invest to be successful in inaccessible learning environments. While I have always wanted to be an educator and feel passionately about teaching, I have not always felt welcome, worthy, or a "good fit" for the place I feel called to be.

After spending time teaching in the K-12 space, I settled into higher education as my professional home. At the moment I hold three roles concurrently: PhD student, staff member helping train faculty and staff, and lecturer at a large, public, Hispanic-serving institution in Texas. In each of these roles, I am perceived—and, at times, perceive myself—differently as a blind woman in academia. In this essay I revisit key moments that got me here.

OH, I GUESS I REALLY AM BLIND

In April of 2001, at nineteen, I had taken my first solo flight to California, and I was sitting alone in the trainers' office,

listening to silence, the whirring of a computer fan, and the sound of my nervous heartbeat. After a long wait, the door finally opened. I heard the click-clack of dog nails and will never forget hearing the guide dog trainer say, “This is Santos! He’s a male yellow lab.” Suddenly, this tall, lean, light-yellow lab was sniffing my face and hands. The trainer then left me alone with this dog that was now, apparently, mine. In that moment, I questioned what I was doing. I had not been someone who had even usually walked with a white cane. Now I’m going to walk next to a giant yellow dog? What was I thinking? Why was I doing this?

I know now this was one of the best decisions I’ve ever made. That choice to get my first guide dog changed my life in ways I never could have imagined. Owning a guide dog was a declaration to myself and to the world around me that I am a blind woman. So much of my life up to that point I had been so focused on not broadcasting that fact. Looking back now, my ability to pass in those previous years kept me from coming to terms with this key part of who I am. People would very often say things like, “Oh, I didn’t know you were blind. You do such a great job!” While this is meant as a compliment, and in my youth, I took it as such, it highlights the misconceptions we have about what a blind person should or shouldn’t be able to do. I have had to work through my own internalized ableism regarding even the use of the word “blind” as a word to identify myself. I can see, after all! But the percentage of the blindness community who are totally blind is very small. I’m not going to notice a wave or nod in

the hallway unless you say something to me. I can't tell if your hand is raised in a lecture hall, classroom, or even a meeting so I will ask you to voice your question aloud. If you've somehow managed to fall asleep during what I am sure is one of my absolutely riveting lectures, I will probably hear your snoring and will crack a joke about you engaging in a snoring contest with my guide dog.

For me, attempting to pass as a sighted person afforded me the privilege of having some level of control over who got to know about this part of my identity and when. So much of the effort I was putting in to fitting into the mold of what I thought I should or shouldn't need was based on others' assumptions about me. Once I allowed myself to engage with the world as a blind person, I was able to accept myself more fully. Even now, many years later, there are times when the privilege of being able to pass as sighted affords me the opportunities to avoid engaging with the systemic biases we have in higher education toward blind people. During COVID, our university was fully online for a period, and while providing training and guidance to staff about creating accessible content, I got to enter the virtual meeting room as just another floating head. During one such meeting with a faculty member, they said "I don't think all of this is necessary. I've never had a blind person in my class. I don't think this is a class they would take." They went on to say more offensive things. My heart sank. It dawned on me that they didn't know that "those people" they were talking about was me. It never occurred to

them that I, as a blind person, would even be in that meeting with them.

When talking about students' choice to disclose their disability, many faculty ask: "Why don't they come talk to me?" The truth is, we have not made it safe for people to disclose their disability in higher education. We have laws, policies, and procedures, but we don't have true acceptance yet. We are still seen as the exception to the rule. We are operating in a system that was not designed for us and in many ways designed to exclude us. I want to acknowledge that as a white, academic professional, married woman, and mother of two children, I am afforded privileges based on how others perceive these parts of my identity. But I also know I can be dressed professionally, wearing my university employee badge, and what gets noticed or discussed first is the dog next to me—the broadcast symbol of my blindness.

Why make the choice to get a guide dog? Why give up the ability to fly under the radar? Harsh reality taught my fourteen-year-old self an important lesson: I am blind, and I need to learn strategies to maintain my independence and safety regardless of how others perceive me. In high school I rode the bus to and from school with my older brother and other kids in my neighborhood. Our afternoon bus stop was on one side of a very busy intersection in Phoenix during rush hour traffic. One day, the bus pulled up to our usual stop, and I realized I was alone and started to panic. I got to the intersection with cars flying by right next to me and pushed

the pedestrian crosswalk button. I couldn't see the walk sign. I was frozen and could not cross the street. I stepped away from the intersection, found a payphone, and dialed my mom's work number with shaking fingers. As soon as she answered I started crying and trying to talk through my tears. "Mom! No one else got off the bus and I can't cross the street!" I was mortified. I was also shocked into reality. Is this what all those Orientation and Mobility instructors who kept bugging me were for?

I realized I did need to learn some things my friends would never have to. They would never stand on a street corner and learn to "read traffic" with their ears and use a white cane. This realization that I couldn't pretend, to myself or others, that I have perfect or even decent vision was the beginning of a journey of self-acceptance. Even though I could understand the benefits of using a cane in my everyday life, I still was very resistant to it. Again, internalized ableism. If I was going to use a mobility aid, I decided it was going to be a dog. I'm blind but look at this awesome dog! At nineteen, it was an easier choice for me. Now, if I am out and about you will find me confident with either my cane in front of me or my current guide dog leading the way. I have come to accept my cane as another helpful tool and not something to avoid at all costs.

The pressure I feel to pass is the result of the messages I received that I don't belong in most places I want to be—that others don't want me there. And those feelings have been my companions throughout my education, as a student, teacher/faculty member, and staff member.

I KNOW, YOU NEVER EXPECTED ME TO BE HERE

In my various roles in higher education, I have had to fight against the feeling that I am somewhere that I don't belong. From classrooms to meeting rooms I have heard some version of "Oh, RaLynn, I forgot! Can you see this? Just tell me (here in front of everyone) if you can't and I'll send it to you afterward." Spoiler alert—no, I can't see it. I am either ignored or called out by name and asked to publicly discuss the limits of my vision. How many people would feel comfortable discussing personal details in a room full of strangers or superiors? While I could share more painful experiences, I feel it is important to simply acknowledge that they did and continue to occur. But I refuse to let them push me out of this place that I work so hard to be a part of. These issues are not specific to higher education by any means, but I would hope that we would be exemplars for how to get this right!

Why stay in higher education given some of the reasons it's so hard to be here? I know that because I am in these spaces, I am able to have thoughtful conversations with our faculty, staff, and students about their own identities as disabled people. My willingness to share my experiences has allowed for meaningful dialogue that led to real change on an individual, department, and campus-wide level. I have been an empathetic ear for folks who need a safe place to vent about the various indignities that we as disabled people encounter on our campuses. Sometimes this leads us to take some kind

of action and other times, just knowing we are not alone in our experiences is enough. I still feel like an impostor just waiting to be found out for not knowing enough, not doing enough, not being enough. But I will continue to work to feel like I really do belong here, even though it doesn't feel that way much of the time. Being an educator is such a huge part of who I am, and, as idealistic as it sounds, I still believe in the ability of higher education to make a positive impact on the lives of our students, faculty, and staff.

READY OR NOT! HERE WE...ACTUALLY, WE'VE BEEN HERE FOR A WHILE

As I reflect on my time in higher education, I desperately hope that we can be more honest about how this field that we love so much comes with systemic barriers with which it has yet to fully reckon. It feels vulnerable and tiring to bear the responsibility to shine a light on the changes that need to be made. And yet, if those of us who are blind don't do this work along with our allies, who will? I encourage all of us who consider ourselves to be blind academics to find and create more spaces where we can share our experiences, our hard-won knowledge, and our assistive technology workarounds, and to support each other on the hard days. We need community to process our experiences.

To our sighted colleagues, please remember that we are blind. Showing up to a meeting or class with an inaccessible

presentation may not seem like a big deal to you, but when it's the sixth meeting we've been in that day where this has happened, we feel it. And it stings. Start by enabling the Accessibility Checker in whatever tool you're using to create content. Many universities offer training or resources for creating accessible content. Or simply Google something like, "How to create an accessible PowerPoint/email/Word document" and find tutorials and videos to walk you through it. Yes, we have assistive technology and coping mechanisms to manage this, but you have no idea the toll this takes on us day after day. It may seem like a small thing to you, but for us, to even experience one single day where we didn't have to do so much extra work just to have basic access to materials that you take for granted, would be extraordinary. We experience so much inaccessibility that when something is accessible and we can tell someone took time to consider it as a priority, we notice. Every time.

To our university communities and higher education in general, don't be so surprised we're here. There are many people with disabilities around you. You just probably don't know what those disabilities are or how they impact your colleagues or your students. Expect us to be here. Plan for it. Encourage it. Be a safe place for us to disclose this information to you if we choose. If no one in your classes or department has ever told you they have a disability, this is likely an indicator that it doesn't feel safe to do so. Take a look at how accessible your course materials are. Create a statement letting folks know that you are committed to creating a welcoming environment

and provide multiple ways to provide this feedback, including anonymously. Do the hard work of looking at the assumptions you are making about who is or isn't in your class or on your campus. We have a unique opportunity to create safe and welcoming learning spaces. Let's make sure we are including disabled people in that vision and at the tables where decisions are being made.

CHAPTER NINE



ADELANTE

Plugging Through Higher Education

Karen Arcos

INTRODUCTION

I am an early-career cognitive scientist. I am honored to be a former University of California President's Postdoctoral Fellow and a National Science Foundation Graduate Research Fellow. Additionally, I am a first-generation, totally blind Latina woman and am bilingual in Spanish. I was raised in Los Angeles, California, in a bicultural, immigrant household (Colombian and Mauritian), so I appreciated the cultural

similarities and differences in lifestyle. As a result of my retinopathy of prematurity diagnosis, I learned braille, as well as to use a white cane and screenreaders on various operating systems.

The peer-reviewed, psychological research my collaborators and I have published thus far has developed my desire to pursue research on a long-term basis to benefit marginalized communities. (See, for instance, “Perks of blindness: Enhanced verbal memory span in blind over sighted adults,” as well as other publications (Arcos et al., 2022a, 2022b, 2025). Much remains unknown about neuroplasticity and cultural influences on learning, leading to my social psychological interests in intersectional identities.

Being totally blind at only months old, I offer the K-12, undergraduate, and graduate student perspectives of a blind student and employee. While my higher education experience has been fulfilling overall, I would be remiss to not emphasize the culture shock I experienced beginning as an undergraduate at University of Southern California (USC). USC was about ten miles from home. My public high school enrolled over 60 percent Latinx students in 2024 (Data Reporting Office, 2024). Over 70 percent of residents are Latinx in the surrounding university neighborhood, unlike this predominantly white institution, which enrolls about 15 percent Latinx students (Niche.com Inc., 2024; University of Southern California, 2024). My parents drove Toyotas, while some classmates rode in BMWs. Some classmates were one of several generations in their families to graduate from USC, whereas I was the first in

my family to study there. Some involved in Greek life might eat cooked meals at their chapter houses, whereas I was thinking about what to eat next and how to get to the dining hall despite having a meal plan. I had not thought to learn a walking route to the dining hall with an Orientation and Mobility instructor, though it was visible from the on-campus apartment where I lived with an international roommate. I only learned about how to get to classrooms at first and met few students with visible disabilities. Needless to say, I felt out of place and questioned my sense of belonging until I made long-term friendships with ethnically underrepresented minority (URM) students.

I sought to reconcile my multiple underrepresented identities beginning as an undergraduate. I studied and lived on campus at USC—a medium-sized private university. Then, as a graduate student, I resided at University of California, Irvine—a large public university—also near home. I went from being one of roughly three blind students taking advanced K-12 courses to being the only blind student and one of about three Latinx graduate students in my major department. As a fully remote postdoc at University of California, Santa Cruz, my goal was to create community in and outside my lab at this large, public university during the COVID-19 pandemic.

While undergraduate accommodations were more straightforward, access became more complex though doable as I engrossed myself in conducting research. Accommodations shifted from testing and course-related accommodations

during undergrad to technical ones like accessing programs and websites to efficiently conduct lab research.

Here, I focus on how my gender, ethnicity, and blindness intersect, as well as on how their intersection influences my perceptions of others' responses to my identities.

IDENTIFYING INTERSECTING DIMENSIONS OF IDENTITY

Class, gender, and ethnicity influence how I perceive and respond to my blindness. Learning the term intersectionality during a Chicano/Latino Studies graduate course taught me I could concisely describe my background and normalized that I am more than just these traits alone (Crenshaw, 1991).

I find family and the general public respond differently to my blindness, possibly due to cultural background. Latinxs seem to exhibit inspirational porn, or objectifying a disabled person completing everyday tasks like crossing a street in wonder or amazement for the benefit of nondisabled individuals (Grue, 2016; Nario-Redmond et al., 2019). This may possibly occur because they see blind people completing activities they cannot imagine doing with their eyes closed, because those I primarily interact with come from working class backgrounds, and because I am the first to earn a PhD in my maternal family. In contrast, whites seem more interested in knowing my blindness-related experiences. In both cases, I breathe, pray for patience, and briefly mention relevant

findings on brain adaptation and anecdotal experiences. I may also thank Latinxs, depending on the comment.

I support both interdependence and independence views. The interdependence aspect is more consistent with my Latino culture; I use interdependence to accept my need for help if disoriented rather than pretending I can do everything independently in situations some may find dangerous. Some in the blindness community want blind people to believe they can do anything and everything independently. In my opinion, no one's fully self-sufficient. To affirm my independence, I use the well-meaning compliments I receive as motivation when I find some faculty in academia or other professionals intimidating.

I've come to accept educating those in and out of academia about blindness and my needs, as exhausting and monotonous as it might be. This saves them and me from struggling to interact later with inaccessible materials. I turn compliment moments into educational opportunities. When told that I read braille fast, for instance, I explain braille takes longer to read than print according to research and discuss the need for extended time to read.

CHOOSING AND REPRESENTING EXPERIENCES

My ethnicities' emphasis on collectivism helps me to accept that everyone relies on others to some extent, sighted or blind. As intimidating as requesting help continues to be for me,

especially when navigating physically or figuratively, I apply interdependence to accept my need for help. The same applies when I doubt my abilities or feel my reasoning is not to par as an early-career researcher. I prepare questions and articulate my messy thoughts as clearly as possible.

I've come to appreciate that interacting in my environment through multiple senses is expected, given study results. For instance, sighted individuals engage in touch more passively while those who are blind feel more actively. Writing about tactile acuity differences during graduate school helped me understand why I notice small details like a scratch on my mom's arm; she may not realize she has it until I point it out and she looks at it as opposed to touching it. Similarly, the occipital cortex—the brain area responsible for vision—activates when braille readers who become blind early visualize linguistic information like letters and numbers, whereas it activates less in those who lose vision later in life. Understanding this makes me realize why I tend to visualize information being spoken to me in braille like a security code I'm memorizing in the short-term.

I use many parents of blind children's positive outlook on me as motivation to keep moving forward to show them and myself what is possible with persistence and collaboration. In the Latinx community, I seek to normalize blindness, so parents allow their children to participate in more opportunities; over protection is a common topic. Reflecting on my experiences reminds me how my parents let go of me over time while still being supportive, and most extended family

followed suit. From my grandma teaching me to get off my bed as a toddler to my mom teaching me to fold laundry and self-advocate, being comfortable with living skills has come with time. I credit my dad with subtly warning me of the culture shock and stress I'd experience in higher education growing up. I thank him in spirit each time I've face verbal microaggressions since, as he put it, "I tell you the way it is."

I remind myself to be proud of where I'm from and to share with others when relevant to expose the cultural diversity behind even just the blindness disability group. I am vocal about how culture shaped me to show others that we are more similar than different as much as I may think others tend to zoom in on my blindness when first interacting with me. Starting around my late twenties, I warned people about code-switching between English and Spanish rather than apologizing when I do. I also use humor to hopefully make others feel comfortable talking about my blindness instead of avoiding the topic or bringing it up indirectly with terms like "your situation." When others sympathize about their or my diagnosis, I discuss the positive ways blindness has shaped me like developing my resilience, persistence, and problem-solving abilities.

My scientific training also allows me to appreciate visual information, that is, colors, the concepts of transparency, and depth perception. As a child, I felt frustrated with these unimaginable concepts. I now understand concepts like the color spectrum. I use analogies like imagining a faraway sound when trying to grasp transparency while seeing something far

away through a window or mirror. Thanks to changing my thought process, I am much more interested now in understanding the mechanics behind how the eyes and brain communicate compared to childhood and adolescence when I was more concerned with how my blindness impacted non-romantic social relationships. I get excited about having CT or MRI scans done instead of dreading them. I can experience in real time what classmates saw in pictures.

OFFERING HOPES AND INVITATIONS

To faculty, I offer the following suggestions from my time as a student. Think of and apply as many senses as possible when teaching unfamiliar information. For example, several professors used rubber brain models to teach me about mapping brain areas to one another as opposed to only using diagrams of lobes, etc. Former teachers and my graduate adviser 3D printed a brain hemisphere. We added braille labels to the different regions using fishing line and paper so I could better understand areas' shape and visualize them in three dimensions.

Offer inclusive research studies and lab-related experiences. Think beyond alternative assignments in lieu of participating in studies for course credit. To encourage more experience conducting research, create more accessible opportunities in lab settings by transcribing interviews or analyzing existing quantitative or qualitative data according

to where students are academically. Consider how you might make research studies more accessible, for example using radio buttons rather than sliders on surveys or disabling countdown timers depending on design. To university leadership, consider joining the American Association for the Advancement of Science's STEMM Equity Achievement Change initiative (American Association for the Advancement of Science, 2024). Its purpose is to systemically transform higher education institutions to support all students and scholars in science, technology, engineering, mathematics, and medicine (STEMM) fields using evidence-based strategies.

Consider accessibility during course design so as many students can be held to the same standards as possible while receiving equitable opportunities. When I met the director of the honors program for my undergraduate department and expressed my interest in applying, she responded, "I guess you can apply." After a semester or so of showing her what I could analyze with my thesis adviser, who I met after another URM professor exposed me to qualitative research, the director submitted graduate recommendation letters on my behalf. I earned a research award following her nomination. I thus needed to demonstrate my capabilities first to change her perspective.

Consider how accessible websites or programs are from the user and content creator perspectives: for example, Qualtrics Survey Solutions. While Qualtrics is mostly accessible for taking surveys, its survey builder remains inaccessible as of 2024. Decide on and design classroom materials months

early to ensure they are accessible. This is especially the case for math and science content, some of which takes months to transcribe into braille the more graph-heavy it is.

As an instructor, I've learned the importance of continuing to request/document my accommodations and of working with students to accommodate their needs. Receiving consistent accommodations as early into the term as possible is most helpful. When teaching an in-person memory and writing seminar for the first time, the assistant who managed inaccessible touchscreen technology was quite helpful. He'd set up, guide me throughout the classroom space during group work time, and ensured I was projecting relevant content on screen. However, I did not receive assistance with grading written assignments. Grading alone for much of the term affected my physical and mental health as well as productivity due to much sleep deprivation and stress preparing content. Despite asking for assistance before the beginning of term, I received grading assistance shortly after experiencing a medical emergency. Why the lack at first? Due to a small class size. Equal treatment compared to other instructors? Yes, since course size was a determining factor. Equitable? No, because braille takes twice as long to read; learning management systems could also be more accessible, and I had additional responsibilities beyond teaching.

To hiring committees or managers, please realize that qualified candidates who happen to be blind can offer much to your worksites if both employers and potential employees give themselves the opportunity to collaborate. Until science

improves access-wise, early-career blind candidates may possess less experience in some areas compared to others. In my case, I have more research than teaching experience. Denying us career opportunities regardless of reason staggers our chances at professional growth and of pursuing our fields of study; if publications are relevant, consider publications' quality over quantity.

Taking accommodations into account and adopting a growth mindset matters both for potential blind higher education professionals' benefit and to improve existing organizations/companies' landscapes. Blind employees may experience more professional growth and self-confidence pursuing their fields. They may be more productive if mentally and physically healthy. Collaborating may yield higher quality projects if multiple perspectives are considered as this volume's authors do.

REFERENCES

- American Association for the Advancement of Science. (2024, June 6). *AAAS SEA Change: Mission*. <https://seachange.aaas.org/about/mission>
- Arcos, K., Jaeggi, S. M., & Grossman, E. D. (2022a). Perks of blindness: Enhanced verbal memory span in blind over sighted adults. *Brain Research*, 147943. <https://doi.org/10.1016/j.brainres.2022.147943>
- Arcos, K., Harhen, N., Loiotile, R., & Bedny, M. (2022b). Superior verbal but not nonverbal memory in congenital blindness. *Experimental*

- Brain Research*, 240, 897–908. <https://doi.org/https://doi.org/10.1007/s00221-021-06304-4>
- Arcos, K., Covarrubias, R., & Storm, B. C. (2025). Examining the potential benefits of affirming values on memory for educational information. *Behavioral Sciences*, 15(8), 1033. <https://doi.org/10.3390/bs15081033>
- Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43(6), 1241–1299.
- Data Reporting Office. (2024, June 5). *Enrollment by ethnicity* John Marshall Senior High (CA Dept of Education). <https://dq.cde.ca.gov/dataquest/dqcensus/enrethlevels.aspx?aggllevel=School&year=2023-24&cds=19647331935568>
- Grue, J. (2016). The problem with inspiration porn: A tentative definition and a provisional critique. *Disability & Society*, 31(6), 838–849. <https://doi.org/10.1080/09687599.2016.1205473>
- Nario-Redmond, M. R., Kemerling, A. A., & Silverman, A. (2019). Hostile, benevolent, and ambivalent ableism: Contemporary manifestations. *Journal of Social Issues*, 75(3), 726–756. <https://doi.org/https://doi.org/10.1111/josi.12337>
- Niche.com Inc. (2024, May 31). *90006 demographics and statistics*. Niche. <https://www.niche.com/places-to-live/z/90006/residents/>
- University of Southern California. (2024, May 27). *Facts and stats*. USC. <https://www.usc.edu/we-are-usc/the-university/facts-and-stats/>

CHAPTER TEN



FROM THE BACK OF THE MIRROR

Nicholas S. Racheotes

INTRODUCTION: GETTING TO KNOW US

T. S. Eliot had it right when he wrote, in “The Love Song of J. Alfred Prufrock,” that we prepare faces to meet the faces that we meet (Eliot, n.d.). My CV says, if read with assiduity, that I’m seventy-six years of age, was educated in the Boston Public schools, hold an MA in history from Brandeis and a PhD in history from Boston College, ended my full-time teaching career as professor of history at Framingham State University, occupied various administrative posts in

the academy, am currently a research associate at the Davis Center for Russian and Eurasian Studies at Harvard, have published in the field of Russian history, and am also a published poet. So, after all this, what questions remain? Foremost, tongue in cheek, is, do I get the job? Secondly, do my or does any set of credentials omit vital information that audiences should know?

What the aridity of any summary, any interview, any pose of self-reflection, and any ardent denial of being anyone's model cannot capture are the sheer joys of teaching, the fathomless gratitude for being respected by colleagues, the fulfillment stemming from aspiring to be a good citizen of the academic community, and the humbling yet rewarding elements in having one's scholarship accepted. Quite simply, in what you will be reading below is a set of spontaneous observations from the back of the mirror on my meandering road to higher education with some of what that implies.

NOT SO AMAZING GRACE

Reversing the polarity of John Newton's all too famous hymn, I once could "see," but now, I'm "blind" (Newton, n.d.). If there is an "amazing grace" to this reality, it lies in the lifelong wisdom of accepting a set of inherent tensions. There are, like it or not, limitations imposed by being without sight, and these will never completely go away. At the same time, minimizing

these is a demanding, but not necessarily solitary, endeavor. Welcoming the help of others comes along with not being overly dependent upon it. Swallowing blood at an offensive statement is offset by being someone with whom others wish to be friendly. Without denying the reality of being largely without sight also involves the realization that slips are going to come more often than one might like, reminding one of the exactions of the world one cannot see.

Put another way, “the bliss of solitude” coexists with the rewards of collaboration (Wordsworth, n.d.). There were legions of kind readers, who made available all that material outside the scarce recordings and braille volumes, which existed during my years of study. At an even more specialized level, wonderful, patient, and oh-so-generous persons, fluent in Russian, French, and modern Greek, opened and still keep wide access to the treasury of these cultures. Family, dear friends, and valued colleagues persist in supporting both my scholarship and creative side. Ultimately, mine is the blame and responsibility, theirs is largely the credit.

We could easily be lost in this thicket of truisms, but as someone who has few friends with limited vision yet who has had leadership positions as a volunteer with the National Braille Press and what was at the time Recording for the Blind and Dyslexic, someone not steeped in the rich literature on disability despite having written on the blind and visually impaired in Russia, and someone who was raised and educated to be part of the world of the seeing, I confess to a level of discomfort with being in any sense defined as a blind

person. At the same time, at my advanced age, I'm no longer upset at such an attribution.

If pressed, I would have to confess to being a Christian, a husband, an American, an educator, a scholar, an author, and a musician, in that order. Should you cavil at any of these, you may stop reading now. However, please note that the above inform my blindness and not the other way around. Of greater significance, I and my professional life inadequately reflect all those formative, beneficial influences: loving, encouraging parents and brothers, devoted friends and colleagues, inspiring teachers, books I've read, songs I've played, and much that doesn't come to mind. The trick of the light in this funhouse mirror is that all these supposed identities matter and don't figure as I shall allege below. The occasionally repeated bromide that the examined life is the only one worth living does not resonate with me as it perhaps should. When I bump against such considerations, I resort to something a bit divergent. Without losing one's integrity, always to be aware of how others perceive one, seems crucial to me. Being able to speak and listen to oneself at the same time in the hope of making every class, every collegial exchange, every relationship welcome and fruitful are keys to more than academic life.

WAR-AND-PEACE STORIES

At this point in an overly self-centered essay, I deploy a thick filter to catch the broken eyeglasses, bruised shins, chipped

teeth, and tears of frustration that characterized my athletic childhood. Recalling that the philosopher who supposedly said, “what doesn’t kill us makes us strong,” ended in an asylum for the mentally ill, I prefer to think that what doesn’t kill us reminds us to accept what we cannot change.¹ Reverting to the title of this volume, I would note the often but not altogether healthy conflict between how individuals and institutions must “shift” for mutual benefit. The elasticity of “reasonable accommodation” is a hole which this rabbit prefers to jump over after having negotiated it with some positive outcomes for students and colleagues. I would prefer to relieve the stress with a war story drawn from a successful job interview.

Interviewer: Dr. Racheotes, you don’t see. How are you going to control a college classroom?

Dr. R.: I didn’t know that you have to control a college classroom. After all, I assume the students want to be there, and if they are in doubt, my job is to make them want to be there.

Int.: No, I mean, how can you tell whether they’re bored? After all, you can’t see them.

Dr. R.: No, but I can hear them. They might be sighing, clicking their pens, squirming.

Int.: What do you do then?

Dr. R.: Then, I tell a joke.

Int.: And if they’re still bored...

Dr. R.: Then, I tell a dirty joke.

Keeping in mind that the above took place in August of 1978, that neither the interviewer nor the vast majority of persons on that campus had ever met a blind person, that the position offered was only for part-time, that you may well be grinding your teeth at all the improprieties bristling in the dialogue, thirty-five years, thousands of students, regular promotions, remunerative employment, lasting friendships, and the opportunity to practice the craft for which my family and I sacrificed so much ensued. Were there instances of inadvertent ignorance and stunningly insulting behavior along the way? Of course, but these were fleeting. Should I say, “amazing grace”?

TODAY’S SERMON

If you’re reading this, you’re already in the choir, so, this is the song I hope you’ll consider singing to those who aren’t. First, we cheat dignity when categorizing. Having gone to a middle school that was overwhelmingly African American, I learned early that there were insurmountable limitations to thinking in terms of “you people.” The lyric in Bobby Darin’s “Simple Song of Freedom”—“I just want to be, someone known to you as me, / And I will bet my life you want the same”—may have its solecisms, but holds a vital truth (Darin, n.d.). Second, what may cripple any disabled person, and I choose the term cripple deliberately, is anger and resentment on both or either side. Despite what most of us among

blind academics, my successful friends with limited or no vision, and other disabled persons among the near and dear have suffered, they invariably remain positive, determined, dignified, and, yes, even witty.

To be candid and perhaps even a bit vulgar, if we shouldn't and don't expect every African American employee and colleague to be "super fly," if we don't expect every female employee and colleague to be "wonder woman," is there any reason why we should require those who would make wonderful colleagues, gifted teachers, respected scholars to be "super blink"? To be admired for what one brings to the dance, rather than idealized for imagined gifts, to be welcomed as a friend and colleague, rather than isolated as an unapproachable genius, are goals to which we can both aspire and attain. I would end these rhetorical flourishes with an even more pressing objective, to fashion institutions of higher education into communities where varying perspectives are encouraged, connections between knowledge and wisdom are forged, curiosity is instilled, passion and the quest for objectivity productively both clash and support one another, and comfortable challenges are issued to anyone who wishes to be part of it. In short, when I was before a class, seated in my office, doing committee work, or at this keyboard, I was and am determined to be the beneficiary, yet not the captive, of all these identities. Those centuries-old walls defended free inquiry, and those congested halls were pathways to the mutuality of learning.

NOTE

- 1 “What does not kill me makes me stronger,” one of the widely quoted and equally misquoted aphorisms, has been attributed to Friedrich Nietzsche’s *Twilight of the Idols*, published in 1888, the year before, practically without sight, he died in a mental institution.

REFERENCES

- Darin, B. (n.d.). “Simple Song of Freedom” lyrics. Musixmatch. Retrieved April 11, 2024, from <https://www.musixmatch.com/de/songtext/Bobby-Darin/Simple-Song-of-Freedom-live>
- Eliot, T. S. (n.d.). “The Love Song of J. Alfred Prufrock.” Poetry Foundation. Retrieved April 11, 2024, from <https://www.poetryfoundation.org/poetrymagazine/poems/44212/the-love-song-of-j-alfred-prufrock>
- Newton, J. (n.d.). *Hymn: Amazing Grace*. Hymnal.net. Retrieved April 11, 2024, from <https://www.hymnal.net/en/hymn/h/313>
- Wordsworth, W. (n.d.). “I Wandered Lonely as a Cloud.” Poetry Foundation. Retrieved April 11, 2024, from <https://www.poetryfoundation.org/poems/45521/i-wandered-lonely-as-a-cloud>

CONCLUSION

Considerations and Recommendations for Moving Toward Equity Culture

Alison Cook-Sather

The authors of this collection offer stories of selfhood that illustrate both what faculty author Nicholas Racheotes calls “common but not comparable” experiences—and importantly different ones. What can we learn from the commonalities and the differences these essays reveal, both about students’ and faculty members’ particular journeys navigating higher education with blindness or low vision and about the responsibility everyone in higher education has to develop or deepen

equity mindsets and practices in themselves and in others? What might we come to better understand about the continua along which people relate and respond to challenge—across the day, a phase of life, all of life—conditioned by culture, including the culture of achievement in institutions of higher education? And how might we understand and pursue shifts in mindset as relational as well as individual?

To inform this concluding reflection, I invited any of the eleven authors who were so inclined to read across all ten essays and share with me and one another what struck them. Among us we identified the themes that follow as critical to “shifting blind identities” in the third sense of this phrase that I offered in the introduction—as what hinders and what could help members of higher education communities shift conceptualizations of blindness and low vision away from only deficits, absences, disabilities, and liabilities to be managed and toward dimensions of identity that, like other differences, can require particular contexts, attitudes, and practices to support success and can also inform and enrich everyone’s experience of education.

The themes we identified across essays include:

- acknowledging the costs of behind-the-scenes labor
- striving to balance independence and interdependence
- turning sources of challenge into catalysts for empowerment, and
- embracing the necessity of communication as education.

These themes inform and are informed by one another, and they also overlap; they are not mutually exclusive

categories. The first one and the last one serve as bookends—one that names what needs to be shifted away from and one that names what needs to be shifted toward. I frame the middle two sections in both/and rather than either/or terms to signal the challenging complexity and also the encouraging possibility that those themes strive to capture. As I noted in the introduction, these essays are situated in a present that can and will continue to evolve. They are also students' and faculty members' experiences, not those of staff members or administrators. More stories of the experiences of those who are not students or faculty are needed to deepen understanding and are no less essential to higher education. More work is also needed from individuals who identify as sighted regarding how they conceive of blind identities “from the outside in.”

To inspire further reflection that will, I hope, inform action, I include at the end of each section below considerations in the form of questions formulated by essay authors and by me in response to their essays. An overarching question to keep in mind when reading across these themes is this: Why are these understandings and ways of being important?

ACKNOWLEDGING THE COSTS OF BEHIND-THE-SCENES LABOR

The behind-the-scenes labor on the part of students and faculty with blindness and low vision has high and enduring costs. I start with this theme because it offers one answer

to the question of why the understandings and ways of being that the authors of this collection call for are important. They are important because these and other students and faculty with blindness or low vision are discriminated against and harmed—daily and cumulatively—by the structures and practices of higher education, and all of us in academia are responsible for shifting that reality. The current reality that the authors of this collection—and those whose stories are not told in these pages—live is that thirty-five years after the passage in 1990 of the Americans with Disabilities Act (ADA), higher education has failed to meet its requirements. Many higher education contexts embrace neither “barrier-free design” (Hamraie, 2013) nor Universal Design for Learning, both of which would change the structures and practices of colleges and universities. Beyond that, though, most institutions of higher education have not engaged in the shift from accommodation culture, inconsistently and inadequately enacted, to equity culture, which includes recognition that all people on the campus should have the opportunity to thrive (Cook-Sather & Cook-Sather, 2023) and that the creation of such opportunities is necessarily a collective as well as an institutional and individual responsibility.

Every essay in this collection includes examples of the behind-the-scenes labor that these student and faculty authors must undertake—every day, and year after year. These examples illustrate how the necessity of doing this additional labor militates against engagement and success, and

how the labor is necessary both in daily life and in particular relation to academic responsibilities. For instance, Rose West explains: “We must make those around us more comfortable with our disability and our existence. When you are only twenty, and are still trying to figure out who you actually are, however, this pressure further complicates our already complex understanding of the self.” Rose continues that the relentless labor of putting sighted people at ease hinders her experience of college as a place where she can access “the same way as anyone else” the goals that all students have—to learn, find community, and better understand themselves—and too often makes her campus a place where she “must address other people’s discomforts and anxieties instead of better addressing my own.”

Regarding academic responsibilities, Morgan Cook-Sather explains: “It’s not until a professor stands behind me and sees me navigating the zoom feature of my laptop that they even begin to understand what it takes for me to do the work for their class.” Not all faculty have the opportunity or take the time to see that, though, and, as Morgan continues: “No one sees the amount of invisible labor that goes into gaining access to course materials, the mental labor of continuing to follow up and advocate for myself when systems are not working for me, or the overall time and energy it takes not only to ‘keep up’ but also to excel.”

These social and academic forms of labor are intensified when the blindness or low-vision aspect of a student’s identity intersects with other dimensions not adequately recognized

and addressed in higher education. As Ibeth Miranda reveals, for example, describing her experience as a first-generation college student: “There has been so much to learn about being a ‘college student,’ and whatever exactly that even means, before even adding the layer of blindness to the equation, which I would have to learn on my own.”

Faculty authors also detail the kinds of behind-the-scenes labor they must do. H. May provides for others a list of what they wish someone had told them about navigating higher education with a vision impairment, a list that includes points about the labor necessary to gain access and get support. They write: “Although you have a degenerative disability, you will repeatedly be asked for documentation, even when you are requesting the same accommodation you used in the past.” In addition, they remind readers, “Higher ed administrators turn over frequently and each new hire will require you to repeat steps of this process.” The relentlessness of this labor takes a toll. As RaLynn McGuire clarifies:

Yes, we have assistive technology and coping mechanisms to manage this, but you have no idea the toll this takes on us day after day. It may seem like a small thing to you, but for us, to even experience one single day where we didn’t have to do so much extra work just to have basic access to materials that you take for granted, would be extraordinary. We experience so much inaccessibility that when something is

accessible and we can tell someone took time to consider it as a priority, we notice. Every time.

Karen Arcos offers an example from her teaching of how the system that operates according to a certain notion of fairness is not equitable. She explains that, despite asking prior to the start of a particular term for assistance in a small class she was teaching, it was not until after she experienced a medical emergency during the semester that she received any support. She writes: “Why the lack at first? Due to a small class size. Equal treatment compared to other instructors? Yes, since course size was a determining factor. Equitable? No, because braille takes twice as long to read; learning management systems could also be more accessible, and I had additional responsibilities beyond teaching.” Karen’s distinction between equal and equitable is one that student authors Ashley Neybert and Morgan Cook-Sather note as well, also in relation to the additional, behind-the-scenes labor that conflation of these concepts can require of students with blindness and low vision.

These experiences reflect a reality that student author Salar Khan describes in his essay: “Like a lot of folks facing adversity, I have to work harder, think faster, and be kinder to achieve my goals.” And they reflect as well the deeper reality that sometimes extra time, thought, and energy are not enough. Ibeth Miranda narrates a version of an experience all students with blindness and low vision have had. Although she has always done the behind-the-scenes labor of trying to gain

access to materials for a course before the course began, Ibeth has not, on some occasions, received the materials in time... or sometimes ever. In describing one instance, she explains: "I had the syllabus and the reading list that let me know when each reading was due, and yet I was unprepared. Not because I did not prepare. I did everything within my power to prepare, and yet in the eyes of my professor and peers, I was not prepared." As detailed by faculty authors H. May, RaLynn McGuire, and Karen Arcos, what faculty are required to do on their own time to gain access and get the support they need to do their jobs parallels student experiences, although in many cases no office of access services supports the labor.

Authors' descriptions of their experiences could fill a "display board for the weaknesses of [the] cultural system" (McDermott & Varenne, 1995, p. 327), that is, in this case, of higher education. Are the only choices to find comfort in the perspective that "what doesn't kill us reminds us to accept what we cannot change," as Nicholas Racheotes writes, or to embrace the "super crip" trope, according to which people are inspired by individuals with disabilities who manage and blame those who don't, which Kira McCabe critiques in her essay in this volume and elsewhere (McCabe, 2022)? This should not be the case in a context that ostensibly honors the ADA that prohibits discrimination against and requires reasonable accommodations for people with disabilities (U.S. Department of Labor, n.d.). Instructors, educational developers, staff members in offices for accessibility services, and diversity officers, among others, should make themselves

aware, be proactive, and work in partnership with students and faculty who experience blindness or low vision. The burden of educating and problem-solving should not be placed on people who are blind and visually impaired.

STRIVING TO BALANCE INDEPENDENCE AND INTERDEPENDENCE

One of the key themes that author essays highlight is the challenge of balancing independence and interdependence in the larger socio-cultural context of US and Canadian higher education. The dominant western values of independence and individual achievement undergird structures and processes, and therefore relationships, that are particularly antithetical to equity mindsets and practices. Kira McCabe explores this phenomenon in relation to the tension between agency and communion. Karen Arcos puts the western norm of independence into dialogue with Latinx family and cultural embrace of collectivism, arguing for the value of both. Nicholas Racheotes names the intersection as one between solitude and collaboration.

Independence is closely linked with agency, which Kira McCabe describes as “striving for individual accomplishments, mastery, status, power, and control.” Some forms of agency are empowering, others are damaging, and some are both. Salaar Khan talks about initially not telling people about his vision impairment because, in his words, “I wanted

to be independent, which...I thought meant figuring out my accommodations on my own.” Subsequently, he shifted from that form of agency to a more empowering form when he decided no longer to “do things by myself without burdening instructors or peers,” the results of which were “reduced performance and increased stress,” and instead “realized that collaboration and honesty would be crucial assets for me to thrive and help others do the same.”

H. May’s list of what they wish someone had told them includes many items that require one to do the work oneself, alone, without understanding or support—necessary, not chosen, independence and agency. Having been an independent child before losing her central vision, Kira McCabe describes refusing to ask for help when she was first diagnosed with Stargardt disease, and continuing to wrestle with the independence-interdependence dynamic because, as she writes, “Accepting that you have a disability is one thing; incorporating disability into your identity is another.” RaLynn McGuire describes first refusing to accept that she could not see to cross a busy street at her childhood bus stop—and then choosing to get a guide dog as an empowered and empowering form of independence. Forms of agency as both burdensome individual responsibility and empowering self-direction tangle in authors’ experiences of higher education, and, as the essays in this collection document, each individual experiences that tangle in different ways at different moments.

Experiences of interdependence or communion are also complex. “Striving for love, friendship, and helping other

people,” as Kira McCabe describes communion in her essay, is precisely what drove Kira’s offers and acceptance of help in the Netherlands; the commitment that underpins Camp Abilities that Morgan Cook-Sather describes; the care and attention of the group of “amazing friends” Salaar Khan acknowledges; and the support of the “family, dear friends, and valued colleagues” Nicholas Racheotes names. These authors might not immediately accept love, friendship, or help, although all would, no doubt, quickly extend these to others. This paradox is part of the struggle, and several authors integrate discussion of that struggle into their essays. For instance, Ibeth Miranda shares her complex and sometimes contradictory experience of how her Mexican American family, for whom sense of communion is strong, always tried to “protect” her “even if it was at the expense,” she explains, “of my own personal growth.” Ashley Neybert and her dissertation adviser Martin Storksdieck devote their entire essay to illustrating how they have turned what could be moments of independence that are isolating into experiences of interdependence and communion, seeking points of connection that foreground humanity over dwelling on differences.

In relation to these efforts to balance independence and interdependence, essay authors struggle with the complex intersection of wanting and needing help and knowing that most people are happy to offer it, worrying about and not wanting to be a burden, and recognizing that the notion of total independence is a myth. Morgan Cook-Sather, Rose West, and Salaar Khan offer examples of several aspects of

that complexity. About asking for and offering help, Morgan writes: “I realized, through my own experience of being hesitant to be vulnerable and ask for help, that people, once they know what is going on, really do want to help.” About the threat of being a burden, Rose writes: “I have to work as hard as possible just to prove that maybe I am redeemable, and assure the world that I’m not a charity case.” And Salaar recounts how worries get reinforced: he explains how he has “personally had administrators who approached my requests with doubt and made me feel like a burden for the help I needed”—an approach, he notes, that “only discourages disabled folks from succeeding and limits people’s potential.” Sometimes people feel that the only place they can reliably find help is with those who share dimensions of their identity: Karen Arcos recalls that, as a student, she “only learned about how to get to classrooms at first and met few students with visible disabilities,” and that she also “felt out of place” and questioned her sense of belonging until she forged friendships with ethnically underrepresented minority students.

Balancing asking for help and people’s responses to those requests can be challenging if the responses are uninformed. As H. May explains, when they went to their provost “in her role as the administrator tasked with overseeing faculty concerns, not as a potential friend or aid provider,” that person made several inappropriate and unwelcome offers, such as to pray with H. and to drive them to appointments, “but provided no clarity as to the process by which to request accommodations”—the institutional structure and process, as well as

human relationship, that would have been helpful. Achieving the kind of equanimity Nicholas Racheotes describes can be challenging: “Welcoming the help of others comes along with not being overly dependent upon it. Swallowing blood at an offensive statement is offset by being someone with whom others wish to be friendly.”

Kira McCabe captures the complexity: “Being disabled means that sometimes you need to ask for help. But when internalized cultural values emphasize independent living and self-sufficiency, what should you do?” Ashley Neybert and Martin Storksdieck suggest reaching for connections across cultures and experiences. But in the face of the kinds of barriers Iboth Miranda encountered when wanting to pursue the study of history and its inaccessible primary sources, it can be hard to sustain the commitment to remain in higher education that RaLynn McGuire describes in her essay. Even though structures, practices, and some people’s way of being have consistently made RaLynn feel that she does not belong in the place she most wants to be, she stays because she believes “in the ability of higher education to make a positive impact on the lives of our students, faculty, and staff.”

Questions for Further Consideration

- Where do the individual and academic community meet and how does each entity negotiate this space?

- At what inflection points must the community take up where individual agency cannot act? At what points could an individual consider a community response early in the process of grappling with a challenge?
- What cultural traits can you draw from your upbringing to create meaningful everyday interactions among those with and without visual disabilities?
- How do you decide, in any given moment and circumstance, how much of the agency and action should lie with the person experiencing blindness or low vision and how much of the agency and action should lie with those, such as instructors, educational developers, staff members in offices for accessibility services, and diversity officers?
- How can everyone in higher education find, as Ashley Neybert and Martin Storksdieck did, points of connection across differences that support the both/and of independence and interdependence that Karen Arcos advocates?

TURNING SOURCES OF CHALLENGE INTO CATALYSTS FOR EMPOWERMENT

Every essay in this collection offers examples of sources of challenge that authors have encountered. Keeping in mind the independence-interdependence dynamic discussed above, I explore in this section how authors turn sources of challenge

into catalysts for empowerment—a transformation that does not eliminate the challenge experienced but does enact the positive forms of agency discussed in the previous section. Authors share numerous examples of this both/and, and here I highlight just one from each essay. I group these examples into shifts of mindset, choices about self-positioning within higher education, and influences on career directions.

In relation to shifts in mindset that turn sources of challenge into catalysts for empowerment, Salaar Khan explains that for years he “felt physically limited” by his intersecting disabilities and let himself “be a captive to this excuse.” Not denying the “physical limitations that are simply a reality of certain disabilities,” Salaar also realized that by prioritizing health, exercise, and nutrition he could improve his confidence, strength, endurance, and mental health. As he puts it: “taking initiative in relation to my own health has challenged the notion that I am shackled by my physical limitations.” RaLynn McGuire’s shift in mindset from denying that she is blind to getting a guide dog was, as she puts it, “a declaration to myself and to the world around me that I am a blind woman.” That declaration informed her choice to be and stay in higher education to model and support her right to be there. Reflecting on a full professional life within and beyond academia, Nicholas Racheotes, as “someone who was raised and educated to be part of the world of the seeing,” feels “a level of discomfort with being in any sense defined as a blind person.” Never accepting the designation although acknowledging the challenges, Nicholas has turned living with those

challenges into various forms of wisdom, such as this: “Being able to speak and listen to oneself at the same time in the hope of making every class, every collegial exchange, every relationship welcome and fruitful are keys to more than academic life.”

Essay authors also explore the dynamic between sources of challenge and catalysts for empowerment in how they position themselves as members of higher education contexts. In her essay, Morgan Cook-Sather writes about two experiences of studying in cultures other than her own that were challenging but also gave her opportunities to redefine herself in ways that clarified for her a commitment to equity work. She explains that her confidence in her DEI leadership role—“the ability to get up and speak to all members of my honor society and tell them I am legally blind—comes from my time studying abroad in Costa Rica during my first semester of college, which allowed me to reset my attitude and my relationship to others.” This kind of self-redefinition for self-empowerment and leadership to support others’ self-empowerment is evidenced in faculty essays, too. H. May describes the intersection of joining “the ranks of the disabled” later in life, re-understanding their identity as a result of their diagnosis of retinitis pigmentosa, and experiencing exclusion in their own institution because of the nonbinary dimension of their identity, and then, because of all of these, trying to “push for systemic transformation.” However, as they note, when engaging in such action, people “run the risk of either being publicly outed as disabled, feeling like they have to publicly out themselves to help abled colleagues understand the realities of the

situation, or, in my case at least, both”— and “in an ableist institution, being recognizably disabled carries risk.”

Finally, some authors narrate turning sources of challenge into catalysts for empowerment in relation to their areas of academic expertise and their professional choices. For instance, after feeling frustrated as a younger student at “unimaginable concepts” such as transparency and depth perception,” Karen Arcos now leans into her scientific training, which allows her “to appreciate visual information” through using analogies, such as “a faraway sound when trying to grasp transparency while seeing something far away through a window or mirror.” Kira McCabe has both studied the concepts of agency and communion and “learned to balance” those, in her words, “despite my disability.” Pursuing academic knowledge that can inform lived experience yields forms of agency that empower while not denying the challenges.

Personal agency also emerges from drawing on lived experience to inform practice. Two of the dimensions of her identity that Rose West discusses in her essay are her childhood cancer and her blindness, the former having led to the latter. Rose does not downplay the devastation of this intersection and the challenges it poses. But she also writes about how the intersection has catalyzed for her a commitment to raising funds for cancer research and about how her initial interest in her political science major originated with disability, as she wanted to become a better advocate for herself and others. This desire is now prompting her to consider pursuing a career in advocacy and support. Ibeth

Miranda also writes about how her experience has informed her career choice. Having encountered repeated barriers to accessing primary historical sources during her undergraduate and master's degree work, Ibeth turned this challenge into a commitment to switch from pursuing a history degree in order to research Mexican colonial history to an education degree through which she will research how assistive technology can improve access in higher education. Ibeth's clarity and conviction transformed what started as a disempowering experience of exclusion into an empowering choice. Similarly, Ashley Neybert encountered the barrier of the inaccessibility of the American Chemical Society entrance exam, which prompted her to shift to pursuing a master's degree in curriculum and instructional design in STEM. Finally, Karen Arcos draws on her lived experience in conducting psychological research to benefit marginalized communities.

Like examples in the previous section of balancing independence and interdependence, the shifts in mindset and approach highlighted in this section are both individual and relational, informed by previous experiences and by potential future experiences, conditioned by wider social culture and the particular culture of higher education.

Questions for Further Consideration

- What mindsets and choices support turning sources of challenge into catalysts for empowerment, both for

- those who experience blindness and low vision and those who do not?
- What is the role of empathy—a term three different student authors use in their essays—as opposed to sympathy, which is often linked with inaction (Gibson & Cook-Sather, 2020), in turning sources of challenge into catalysts for empowerment while still acknowledging the challenge?
 - When, if ever, have you intentionally or unintentionally promoted ableist views of yourself or others? How might you instead use this experience to catalyze empowerment for yourself or others?
 - If you do not experience blindness or low vision, what can you do to more deeply understand the challenges those with blindness or low vision face as part of their identities? Relatedly, from your position as a student, instructor, educational developer, staff member in an office for accessibility service, or as someone in another role on a college or university campus, what action can you take to educate others, change structures and practices, and create more navigable and welcoming conditions for a diversity of people?

EMBRACING THE NECESSITY OF COMMUNICATION AS EDUCATION

This final theme provides a bookend to the first theme, “Acknowledging the Costs of Behind-the-Scenes Labor,”

because it turns attention to what can be done “in the scenes”—in interactions among those with blindness and low vision who navigate higher education campuses and those who lack these experiences. It draws on the hopes and invitations that authors offer in the last sections of their essays that both constitute and invite further education—of individuals and of institutions. I list the points here and then substantiate each one with excerpts from author essays.

- Understand how inaccessible higher education can be
- Recognize identities as complex, and let people define their own
- Consider what words—and also what silence—can do
- Attend to what communicates, with and without language
- Recognize that tools and accommodations are not solutions, people are...but thoughtful use of both can help
- Seek human connections and share responsibility
- Hold higher education institutions accountable

Understand how inaccessible higher education can be

As Ibeth Miranda writes: “Readers must understand how inaccessible higher education can be, and how much harder

students with visual disabilities have to work just to keep up with basic tasks.” Salar Khan similarly states: “I hope that people will understand that the everyday problems of low vision are complicated. Especially in a competitive environment like higher education, student performance matters, and the inconveniences of visual impairment can interfere with these results.” And finally, RaLynn McGuire implores: “As I reflect on my time in higher education, I desperately hope that we can be more honest about how this field that we love so much comes with systemic barriers with which it has yet to fully reckon.” Recognition of a problem is a first step toward addressing it. Framing the problem as one with higher education itself, not as located in individuals living with blindness and low vision, is essential to shifting blind identities in higher education.

Recognize identities as complex, and let people define their own

Kira McCabe calls for recognizing the complexity of identities and of the impact of that complexity: “I hope that readers embrace the complexities of disability identity. It can impact everything in our lives—from how we plan our careers to what we want to ask of our family and friends.” Higher education is for students, as Rose West notes, “a place of transition...where new ideas are revolutionized and

formed.” Directly related to individual identity, Rose continues, “students use college as a chance to find themselves, meet their people, and explore their passions. Blind and visually impaired students are no different, yet we often have our identities defined for us.” As Nicholas Racheotes argues, “we cheat dignity when categorizing,” and he articulates a more respectful approach: “To be admired for what one brings to the dance, rather than idealized for imagined gifts, to be welcomed as a friend and colleague, rather than isolated as an unapproachable genius, are goals to which we can both aspire and attain.”

Morgan Cook-Sather reflects on the complexity of choices those in higher education with blindness and low vision have regarding how to signal those aspects of their identity. She notes that having “identifiers that people recognize—a cane, a guide dog”—can be liberating in that it frees one from having to explain oneself, although it simultaneously means having to prove oneself capable because of what people assume based on that indicator. On the other hand, as someone who often “passes as sighted,” Morgan experiences “the other side of the assumptions, where people assume I can do things that I can’t.” In keeping with other authors’ hopes, Morgan wishes “people could recognize more complexity rather than falling back on either/or assumptions—be open to learning rather than assuming they already know.” Being open to learning includes, as Salaar Khan explains, being willing to “listen to blind people’s needs, not with skepticism, but with empathy.”

Consider what words—and also what silence—can do

Both what is said and what is not said have an impact on the experiences of those in higher education with blindness and low vision. Morgan Cook-Sather asserts that when sighted people casually use the word “blind” to describe daily shortcomings, the effect is to “desensitize the word for people who actually have to use it to describe their real-life experiences.” When a word is carelessly used, people can dismiss serious information such terms convey. Ashley Neybert points to the language used to name vision conditions and the hierarchies and assumptions different terms evoke. Morgan, Ashley, and Karen Arcos remind us of the difference between “equal” and “equitable,” the conflation of which can lead to exclusion and harm.

One way to sensitize oneself to language is to consider cross-cultural communication. The particular cultures and languages students like Morgan Cook-Sather studied, the cross-cultural and cross-linguistic connections Ashley Neybert and Martin Storksdieck developed, and the bicultural use of independent, interdependent, and code-switching practices Karen Arcos discusses are all examples. Translation is constantly necessary for anyone with blindness and low vision as they strive to convey to and convince others of what they need to succeed. The cross-cutting community of those who live with blindness and low vision shares the relentless and often infuriating experience of having to engage in this

constant form of translating, which can lead to developing self-preservation and efficacy-focused strategies such as Salaar Khan's use of humor and RaLynn McGuire's choice to see instances of ignorance as providing teachable moments, as well as to what H. May has come to—exhaustion and giving up even trying in the face of so many barriers, even as they continue to strive to claim their own identities and experiences.

Silence is as dangerous and damaging as careless use of language. As Rose West explains, “sometimes the silence is literal, failing to speak when holding open a door or walking by, forgetting that silence is equivalent to invisibility for the blind.” Other times, Rose continues, “silence is an absence of what should be said: assumptions made instead of questions asked; being spoken about instead of to.” In the final paragraphs of her essay, Rose writes:

If I could call upon anything, it would be for higher education to break the silences surrounding their students with disabilities. It should not be seen as taboo to create an active dialogue about disabilities such as blindness, especially in a community that is meant to transform young minds and spark social movements.

As Audre Lorde (1984) reminded us in her essay “The Transformation of Silence into Action,” silence cannot be counted on for protection, and breaking it can lead to active engagement and solidarity.

Attend to what communicates, with and without language

While carefully choosing words and avoiding harmful silence are two language-based forms of communication that make a difference, other media can also be eloquent and spark meaningful exchanges. In her essay, Morgan Cook-Sather explains that she has two tattoos, both of which “mark milestones in my life of finding my identity” during study-abroad experiences—“where language, culture, and vision intersect for me and two of the places where I have developed my confidence and capacity to communicate across differences.” Her tattoos, Morgan suggests, “are conversation starters; they open a door for people to hear about what’s deeper than the surface, when I explain the meanings behind them.” They also always speak to Morgan herself as “a reminder of my personal growth and also a commitment to continue to hold myself accountable to stay open, rather than close back up again, and to continue to evolve even more.”

H. May writes in similar terms about their tattoo, the colorful snake that covers their forearm and honors Tiresias, “the figure from Greek mythology who was cursed by the gods to shift genders after striking and killing a pair of mating snakes.” The tattoo represents to H. “a source of multi-gendered knowledge” and a refusal “to be shamed for using a cane and embrace and make visible my blindness to others.” H., like Morgan, conveys a strong sense of self-empowerment and also a desire to communicate with others in a way that is educative.

Other forms of communication, like white canes and guide dogs, both immediately signal blindness in ways that make things easier but also can reduce people to only that dimension of their identity. As RaLynn McGuire notes in her essay, she can present herself in professional attire with a formal name tag, but what people notice is her guide dog, eclipsing her professional self-presentation. These forms of signification should not be taken as the whole message; they should not be read as the entire identity of the person.

Recognize that tools and accommodations are not solutions, people are...but thoughtful use of both can help

Structures, resources, and practices can help institutions of higher education comply with laws and can help students and faculty with blindness and low vision in some ways, but they can also create additional labor, as discussed in the first section of this conclusion. Assistive technology tools and accommodations of various kinds are examples, but without a shift toward an equity mindset, these are not enough.

As Ibeth Miranda notes, “AT can be a powerful tool, but often it is not leveraged to its greatest potential to truly help students with disabilities,” and training is lacking, because commitment to fully integrating these technologies is scarce. Similarly, as Salaar Khan notes, “accommodations are not a definitive answer” because they, too, do not change the basic

mindset and culture of higher education, leaving issues “that are more numerous and nuanced than any formalized accommodations can address.”

Universal Design for Learning argues for a shift in mindset and practice that includes teaching strategies such as those that Karen Arcos recommends:

- Think of and apply as many senses as possible when teaching unfamiliar information.
- Consider accessibility during course design so as many students can be held to the same standards as possible while receiving equitable opportunities.
- Consider how accessible websites or programs are from the user and content creator perspectives.
- Decide on and design classroom materials months early to ensure they are accessible.

These are choices faculty can make that take some of the burden off students with blindness and low vision, allowing those students to concentrate on the work of the course, not on accessing it. Paralleling Karen’s advice to faculty, RaLynn McGuire asks all members of higher education to consider accessibility across contexts, such as meetings.

Seek human connections and share responsibility

Numerous times I have mentioned an equity mindset. By this I do not mean some sort of calculation of how to be “fair” by

providing the same thing to everyone but rather a continuous consideration, through dialogue with all involved, of what will facilitate most meaningful engagement and most desirable outcomes. Such a mindset and approach are in tension with mainstream norms and expectations about what matters in and to higher education. To move toward embracing and enacting an equity mindset, Ashley Neybert and Martin Storksdieck call for “openness and a willingness to learn from one another.” They argue that “our shared humanity is based on finding connections, and in being open to learning about each other with curiosity, empathy, and a growing depth of understanding.” These are what inform an equity mindset. Salaar Khan emphasizes “honesty and empathy” and his hope that “people will try to address visual impairment in higher education through open communication with and understanding for one another.” He urges bringing a specific mindset to this challenging work: “I hope that people approach these situations with a positive attitude and try to build collaborative communities.” That attitude, Salaar suggests, and a willingness to take initiative, “are valuable practices for people both with and without visual impairments” and can “create a culture where people of all abilities and backgrounds can work together.”

Salaar’s point is connected to sharing responsibility. He elaborates:

...when problems inevitably come up, faculty and classmates should try to understand the struggles of their impaired peer. I encourage them to listen, ask

questions, and help when they can. On the other hand, my blind friends have their own responsibilities. They should advocate for themselves, even when conditions are hard, because nobody can communicate for you better than you yourself. Moreover, I encourage them to be patient and understanding when people around them make mistakes or do not understand their abilities. I know folks with all kinds of disabilities who can get understandably frustrated by others' ignorance, but the best way to combat this lack of knowledge is not anger. Instead, I hope they will take the steps to choose empathy and honesty.

Sustaining the both/and frame I have endeavored to bring to my discussion of this set of themes, I evoke here the possibility that anger, as H. May describes and that Nicholas Racheotes points to with the reference to “swallowing blood at an offensive statement,” can exist alongside, or alternate with, empathy and honesty.

Salaar also acknowledges that it is hard to ask for help, a point Kira McCabe and Karen Arcos make as well. As discussed in earlier sections of this conclusion, the tension between agency and communion can be hard to manage, and Kira reminds those with disabilities that “there is no ‘right’ way to manage things.” She also asks those who seek to offer support not to “assume people with a disability need help unless they ask for it.” Instead, “listen to what people with

disabilities need.” It is through this kind of dialogue and collaboration that we can share responsibility for making higher education a place where all can thrive.

Hold higher education institutions accountable

If all of us developed the mindsets and engaged in the actions described above, we might be able to begin to hold our institutions accountable for shifting blind identities in particular and for shifting from accommodation to equity culture more generally. This shifting can be part of a larger project, as Kira McCabe puts it, of “providing support for people with disabilities to thrive in society.” That kind of support can start in higher education. Instead of the current attitude, which seems to be a combination of surprise and frustration, we can embrace what RaLynn advocates:

...don't be so surprised we're here. There are many people with disabilities around you. You just probably don't know what those disabilities are or how they impact your colleagues or your students. Expect us to be here. Plan for it. Encourage it. Be a safe place for us to disclose this information to you if we choose.

RaLynn continues that we in higher education “have a unique opportunity to create safe and welcoming learning spaces.

Let's make sure we are including disabled people in that vision and at the tables where decisions are being made.”

Among the decisions institutions of higher education make, with powerful consequences, is not only who is included and excluded but also what is valued. As Karen Arcos argues:

Taking accommodations into account and adopting a growth mindset matters both for potential blind higher education professionals' benefit and to improve existing organizations/companies' landscapes. Blind employees may experience more professional growth and self-confidence pursuing their fields. They may be more productive if mentally and physically healthy. Collaborating may yield higher quality projects if multiple perspectives are considered as this volume's authors do.

Questions for Further Consideration

- What communication approaches would especially benefit students and faculty with blindness and low vision but also everyone? For instance, asking rather than assuming.
- How do we educate to prevent reflexive invidious comparisons? (“You're not like other blind people I've known or read about or listened to or admired.”)

- What might we learn from shared understandings of crossing cultural and linguistic contexts that could inform the particular experiences of students and faculty with blindness and low vision?
- If you experience blindness or low vision, how do you balance sharing your story for communication and education purposes and being seen as your whole self as opposed to readers and writers focusing solely on your blindness and/or other marginalized identities? Where do you draw the line?
- If you do not experience blindness or low vision, how do you learn to avoid harmful silences, terms, and practices? How do you develop affirming and supportive ways of being that make higher education more accessible and welcoming to those who experience blindness, low vision, or all kinds of intersecting dimensions of diversity?

SHIFTING HIGHER EDUCATION

In reviewing this collection, Nicholas Racheotes encouraged me to invite readers and researchers to think further about the insights the set of essays offers and the questions it raises. In his words:

Consider how well founded certain intuitive generalities might be. Waking up to a real and socially imposed

limitation, by extension, unites those with a visual impairment with the racially oppressed, other disabled persons, and even those in various forms of confinement in that all are daily confronted with a stark reality that they must face and with which they must deal throughout their waking hours. Similarly, they may encounter speech patterns, word choices, and other affectations, including being confused with other visually impaired persons in the school or work place, that either require being ignored or tactfully parried. At the intersection of being type cast or feeling as though an impostor, comes again, as with the above, an area for additional research. In the end, while each of the foregoing stories is of great intrinsic value, none pretends to be the whole story, but to inspire the thought and action that will allow those with no or limited sight to become those whose vision enriches higher education.

I add an invitation to others with blindness and low vision to share their stories to contribute to a conversation that can only be inclusive and move us toward equity culture if it is ever widening. And I invite sighted colleagues to listen to, learn from, and act on what authors of these essays call for. Here are some further questions to consider:

- What can higher education environments do to better equip future blind and low-vision students and alumni

for finding and retaining employment? Think of opportunities other than referrals to other organizations or programs. Think beyond what's provided to nondisabled students and alumni.

- How do we keep up the pressure to advance access in step with technological progress and its demands on students and faculty with limited or no vision? For instance, how can we consider both the user and designer perspectives when choosing what tech to use or when designing tech solutions?
- How might everyone in higher education understand ourselves as mutual shifting agents, shaping and shaped by context, relationships, community, and individual choice? Consider the shift as institutions move toward being more welcoming, and we move toward becoming sound academic citizens.

A final invitation: to continue to explore ways of understanding selfhood as more and less agentic depending on contexts as they are or could be informed by the themes noted here, to consider shifts not necessarily as linear but as more looping progressions, and to find and make meaning in community and relationship. Instructors, educational developers, staff members in offices for accessibility services, diversity officers, and all others who engage with students and faculty in higher education should work to raise awareness, be proactive, and partner with students and faculty who experience blindness or low vision to shift blind identities in higher

education. Invite and publish the stories of staff and administrators who experience blindness or low vision. Some of the experiences might be the same as or different from those that students and faculty share in this collection.

The image on the front cover of this book—the close-up of an eye’s pupil surrounded by its iris that could also be an image of a flower or a star trail—yields both a first impression and then subsequent ones when explored further. In the same way, I hope readers of this collection of essays will consider what first impressions of those with blindness and low vision need to be contextualized, questioned, expanded upon, and sometimes replaced altogether. The narratives and the hopes these authors offer can help us all make those shifts.

REFERENCES

- Cook-Sather, A., & Cook-Sather, M. (2023). From reporting to removing barriers: Toward transforming accommodation culture into equity culture. *Education Sciences*, 13 (6), 611. <https://doi.org/10.3390/educsci13060611>
- Gibson, S., & Cook-Sather, A. (2020). Politicised compassion and pedagogical partnership: A discourse and practice for social justice in the inclusive academy. *International Journal for Students as Partners*, 4, 1. <https://mulpress.mcmaster.ca/ij sap/article/view/3996>
- Orde, A. (ed.). (1984). The transformation of silence into action. *Sister outsider: Essays and speeches*. Crossing Press.

- Hamraie, A. (2013). Designing collective access: A feminist disability theory of universal design. *Disability Studies Quarterly*, 33, 4. <https://doi.org/10.18061/dsq.v33i4.3871>
- McCabe, K. (2022, August 29). Opening your eyes to the burdens of a legally blind professor. *Psychonomic Society*. <https://featuredcontent.psychonomic.org/opening-your-eyes-to-the-burdens-of-a-legally-blind-professor/>
- McDermott, R. & Varenne, H. (1995). Culture as disability. *Anthropology & Education Quarterly*, 26, 324–348.
- US Department of Labor. (n.d.). Americans with Disabilities Act, Retrieved May 20, 2023, from <https://www.ada.gov/>

Additional Resources

- Arcos, K., Jaeggi, S. M., & Grossman, E. D. (2022). Perks of blindness: Enhanced verbal memory span in blind over sighted adults. *Brain Research, 1789*, 147943. <https://doi.org/10.1016/j.brainres.2022.147943>.
- Cook-Sather, M. (2021). *Losing sight, finding a new way*. <https://sites.google.com/view/losingsightfindinganewway/home>
- Cook-Sather, M. (2023). *Navigating campus: An accessibility story*. [Video]. W&M Studio for Teaching & Learning Innovation. YouTube. https://www.youtube.com/watch?v=7h17zFUb_k_g
- Donmoyer, C. M. (2022). *Invisible disability: Living with macular degeneration*. Orison Publishers, Inc.

- Khan, S. (2022, November 10). *The courage to continue*. [Video]. TEDxWilliam&Mary. YouTube. https://youtu.be/TKbb5sYYrtM?si=B_kdhHp2L3_bOOeS
- Psychonomic Society. (2023). *Diversity & Inclusion Symposium: Evidence from disability identity and research*. [Video]. YouTube. <https://www.youtube.com/watch?v=LY29NVV9At8>

About the Contributors

Editor

Dr. Alison Cook-Sather, PhD, is the Mary Katharine Woodworth Professor of Education at Bryn Mawr College and Director of the Teaching and Learning Institute at Bryn Mawr and Haverford Colleges. She has developed internationally recognized programs that position students and teachers as pedagogical partners, has over 200 publications and 10 books, and has spoken or consulted on pedagogical partnership work in thirteen countries. Alison is the recipient of several awards, including the Alumni Excellence in Education Award from the Graduate School of Education at Stanford University. Learn more about Alison's work at <https://www.alisoncooksather.com/>

Authors

Dr. Karen Arcos earned her PhD in Cognitive Neuroscience and a Field Emphasis in Chicano/Latino Studies from the University of California, Irvine, along with a Bachelor's in Psychology and a Spanish minor from the University of Southern California. Karen has accomplished feats such as earning the National Science Foundation Graduate Research Fellowship and the University of California President's Postdoctoral Fellowship despite being totally blind. Thanks to those who have helped her be where she is today, Karen is passionate about giving back to her community. She has mentored students on undergraduate and graduate admissions processes, as well as on conducting experimental procedures, to show them that they, too, can pursue advanced degrees. During her free time, Karen enjoys reading mysteries, spending time with family and friends, and hiking.

Morgan Cook-Sather graduated summa cum laude from College of William & Mary in 2025 with a double major in kinesiology/health sciences and French and Francophone studies. She held leadership positions as diversity, equity, and inclusion chair for a national honor society on campus and served on the executive board for Best Buddies. A former athlete at Camp Abilities, she now serves as a one-on-one coach or group leader at various camps and through AmeriCorps and will teach English in France during the 2025–2026 year. She enjoys spending time with friends, playing piano for relaxation, and going on nature walks.

Salaar Khan is a proud Virginia native and current student who spent the last four years studying government and history at the College of William & Mary. He graduated with his Bachelor of Arts in May 2024,

and he is continuing his studies by pursuing his JD at the University of Virginia School of Law beginning in fall 2024. In addition to his academics, Khan has earned recognition for his dedication to public service including as a student organizer, local community leader, political adviser, and advocate for disenfranchised communities.

Dr. H. May, PhD, is a Professor of Theatre at Hobart and William Smith Colleges as well as a professional stage manager and director. Although primarily a theater director, May created a solo film and performance (*Awaiting Tiresias*) about discovering they are going blind. May's publications focus on creating classroom and institutional processes that embrace access as a key for unlocking creativity. Samples of May's creative and scholarly work are available at www.drheathermay.com.

RaLynn McGuire is a lecturer and the Lead Accessibility and Universal Design for Learning Specialist, dedicated to fostering a campus culture of accessibility and UDL. She began her career as a K-12 teacher and transitioned to higher education, where she enjoys training and supporting faculty and staff in creating and remediating accessible content. RaLynn volunteers her time by serving as the Vice President of ATHEN (Access Technology Higher Education Network) and serves on her local Accessible Transit Committee. She is currently completing her PhD, demonstrating her commitment to lifelong learning. In her free time RaLynn is an avid reader, loves listening to and creating music, and spending time with her husband and two daughters.

Dr. Kira O. McCabe is Assistant Professor of Psychology at Carleton University in Ottawa, Canada. She earned her PhD from the

University of Groningen in the Netherlands studying the role of personality in context-specific goal pursuit. She also held postdoctoral fellowships in Australia—one position at Murdoch University and Griffith University—and in the United States at Vanderbilt University.

Ibeth Miranda is a graduate student at Texas State University. She is working on a doctoral degree in Developmental Education with a focus in literacy. Her research interests include the use of assistive technology for reading and making meaning from academic texts.

Ashley Neybert is a legally blind, autistic, fourth-year PhD student in Education with a focus in STEM at Oregon State University. She completed a Master's in Curriculum and Instructional Design at Wichita State University, and her research interests are in making science more accessible and inclusive.

Dr. Nicholas S. Racheotes, PhD, is Framingham State University Emeritus Professor of History and Research Associate at the Davis Center for Russian and Eurasian Studies at Harvard. He has written widely in the field of Russian intellectual and religious history, in addition to the treatment of blind and visually impaired persons in Russia and the former Soviet Union. He lives with his wife Pat in Boston and on Cape Cod.

Martin Storksdiack is Professor of Science Education and Director of the STEM Research Center at Oregon State University. He is also part of an OSU STEM Research Center team that is collaborating with Independence Science, Associated Universities Inc. and Tumble Media, a small company that created science podcasts for children and youth, on a National Science Foundation-funded project titled

STEM Storytelling through Podcasts for Sighted and Blind and Visually Impaired Students (SSP).

Rose S. West is a senior currently enrolled at Swarthmore College, where she is pursuing an undergraduate degree in political science. While balancing her academics, West has been a co-founder of her school's disability association, holds leadership positions for her debate team, collaborates actively with nonprofits, and serves as a near peer mentor and instructor for blind and visually impaired transition aged students in Pennsylvania. Passionate about public speaking, writing, and advocacy, West also is known for rambling at great length about how much she loves her best friend and guide dog, Nara—a beautiful chocolate lab trained by The Seeing Eye.