AFTERWORD¹

Neera R. Jain

What could health science education look like if it started from a place of valuing disability? This question evokes central themes to move our work into a new era: value, possibility, and transformation. These themes developed out of my recent research that explored disability inclusion at several U.S. medical schools (Jain, 2020a, b, c). The findings of that work prompted my dissatisfaction with accommodations as the primary means to enact inclusion in our field. Although accommodations will likely always be an element of inclusive practice, these represent individualized solutions that effect incremental change. They do little to shift powerful discourses of disability as individual inability and healthcare professionals as superhumans that inform educational structures. These discourses represent a threat to all of us, disabled and nondisabled, and hamper movements toward socially just inclusion. A primary focus on accommodations tends to frame disability as a problem to be managed rather than an expected way of being in the world. I believe shifting our gaze to a starting point of *value* has promise to invigorate new ways of working toward inclusion. In this afterword, I share six ideas for centering value in our work.

CHANGE THE NARRATIVE

We must promote alternative narratives of disability, ones that counter those that currently dominate health science education. In the schools I studied, disability was rarely included in curricula beyond biomedical discussions of

¹My initial thoughts on this topic were presented at the 6th Annual Disability in Health Science and Medicine Symposium in April 2019.

“disease processes.” In the few cases where a socio-political narrative of disability was included, the focus was firmly on patients without acknowledgment of peers or practitioners with disabilities. Furthermore, disability was narrowly constructed as those with physical, sensory, and intellectual disabilities. Most students I spoke to had not encountered emancipatory frameworks of disability, such as the social model. Those who were familiar with it did not see it “alive” in their medical school experiences. These conditions fostered students distancing themselves from disability, hesitation to access accommodations, fear of disclosure, and ambivalence in disability identities. Not surprisingly, school officials (faculty and administrators) reported similar, mixed understandings of disability largely rooted in biomedical, individualized, and charity-oriented understandings.

Limited curricula presenting affirming, socio-political accounts of disability in the health sciences are a well-known concern (see, e.g., Campbell, 2009; Iezzoni & Long-Bellil, 2012; Seidel & Crowe, 2017; Shakespeare, Iezzoni, & Groce, 2009; Shakespeare & Kleine, 2013). Rosemarie Garland-Thomson (2017) suggested a program in *disability cultural competence* for burgeoning healthcare practitioners that would include five elements: biomedical decision-making, disability culture and history, accessible technology and design, disability legislation and social justice, and disability cultural competence research. This training, she argues, “requires learning how to flourish as a person with disabilities—not just living as a disabled person trying to become non-disabled” and would benefit “active patients and patients-in-waiting” (Garland-Thomson, 2017, p. 335). I believe such a program would particularly benefit those who straddle the divide as disabled health professionals and could begin to meaningfully shift the culture around disability in health science education.

Similarly, we need to examine our language, policies, and approach to inclusion to consider how these frame disability. Do these policies frame disability as a problem or threat to the profession (Shrewsbury, Mogensen, & Hu, 2018), or is it framed as an expected and valued trait that students may bring to their practice? Are the “problems” disabled students face situated as a lack of accessibility in the environment or individualized concerns that result from one’s diagnosis? In this edition of *The Guide*, we provided renewed recommendations for policy language in line with this approach.

FOSTER COMMUNITY

Fostering disability community is also needed (Jain, 2020c). Many students I spoke to longed for formalized spaces where they could connect with other students with disabilities in the health sciences to discuss their experiences and share resources. When students organically or intentionally developed informal community around disability, this was a significant support. Some students wanted collective spaces where they could receive tailored learning support and strategies for students with learning disabilities and attention

deficit hyperactivity disorders (ADHD) or specialized spaces where they could discuss aspects of mental health and being a medical student with other similarly situated students. Such spaces could provide fertile ground for peer networks and uncover curricular barriers to be addressed.

Some may argue that students with disabilities will be stigmatized further if specialized spaces are created for them. However, in the current climate, such spaces can offer a greater sense of safety and a place to share experiences that currently feel individual and hidden away (Tsai, 2018). Making space for students to come together beyond a forum framed as “support” could promote the idea that, like other diverse lived experiences, students with disabilities have unique value to offer to the professions. Such spaces could foster positive disability identity development and serve as forums to explore integration into professional identity (Fergus, Teale, Sivapragasam, Mesina, & Stergiopoulos, 2018).

TAKE A WHOLE-VILLAGE APPROACH

Inclusion is not a solo act—access is everyone’s responsibility. For this reason, I believe it takes a village to move toward an ethos of value. Disability offices and resource professionals cannot work in a silo, nor can they be solely responsible for ensuring accessibility. Where things worked well at the schools I studied, disability resource professionals (DRPs) worked as a hub, a resource that was integrated into the fabric of schools.

To foster a whole-village approach, bringing others into the mission is important. Developing allies among faculty and administration is necessary to ensure that the flag of inclusion is raised beyond the spaces in which DRPs are present. I also saw how beneficial it was to bring together a group of diverse experts to develop access solutions. For example, one school used a team approach to ensure access in the clinic: a learning specialist, key faculty members (including a physiatrist), an occupational therapist, and the student partnered to identify solutions. Assembling knowledgeable barrier-removal teams avoids gaps in decision-making that can occur in the absence of critical information about the curriculum, assistive technology, or the student’s creative perspective.

INCREASE TRANSPARENCY

The schools I studied all excelled in having an identified point person responsible for students with disabilities, a process for requesting accommodations, and mechanisms for implementing accommodations. These provided students with an anchor and a clear process to access accommodations once approved. Students and faculty, however, generally lacked understanding of the standards used for determining accommodations and who qualifies as “disabled.”

Moreover, students and faculty did not always understand the legal rationale and foundation for accommodations. This created multiple concerns:

- Students did not recognize that the disability office might be able to offer solutions to the problems they were encountering.
- Students who did engage with the disability office were not always aware of their rights, what kinds of changes they could request, or how decisions were made. In an environment where students felt precarious, not knowing how systems worked tended to subvert mechanisms of inclusion.
- Faculty and peers were sometimes skeptical of decision-making and accommodations, increasing the stigma associated with disability and use of accommodations.

For these reasons, it is important to make transparent:

- What do we do as DRPs, and why?
- What counts as disability?
- What kinds of accommodations can be made?
- How do we do our work, and why?

This might entail educating faculty and all students about accommodations, rights, and processes. This education initiative would be an excellent place to infuse a disability-as-valuable ethos, including through stories of successful health professionals with disabilities (see, e.g., Meeks, n.d.).

GET PROACTIVE

Inclusion work must be done proactively, rather than reactively. I see this taking several forms. First, identifying frequent barriers in the educational environment and addressing them for all students, also known as a universal design approach (Burgstahler, 2015; Burgstahler & Corey, 2008; Dolmage, 2005, 2017). This minimizes the need for individual students to act as catalysts for change, which tends to mark them as “expensive” or “needy.” Committing to remediate barriers in the existing physical environment is another way to address this. This could be achieved by earmarking funds for access improvements that are prioritized annually and implemented regardless of immediate need but fast-tracked when an immediate need arises. Planning for access in new initiatives is also essential, ensuring that activities, curricular initiatives, and infrastructure projects are conceived with broad access in mind rather than retrofitting them “as needed” to work around inaccessibility (Dolmage, 2017).

At the same time, we need to anticipate barriers that may arise for all the students we work with. Too often, a proactive approach is only employed for students with physical disabilities, leaving those with less-apparent disabilities without support until issues are raised. Most importantly, we must

not just identify barriers, but also possible solutions to bring to students for consideration. This proactive partnership approach is essential to lessen the burden on students to develop solutions to access problems while honoring their expertise.

TRANSFORM HEALTH SCIENCE EDUCATION

And finally, if we want real equity and inclusion for people with disabilities in the health professions, a focus on improving access through bettering accommodations is not enough. We need real transformation. I believe this starts from deep exploration of what is truly essential about being a doctor, nurse, physical therapist, physician assistant, pharmacist, dentist, occupational therapist, and so on. Alongside this, we need to rethink what is needed from these professionals to provide the best healthcare for all patients. How do we close gaps in healthcare disparities?

I believe disabled people bring value to the professions through their unique ways of being and knowing. Instead of finding ways to “fit students in” to health science education, I wonder how education programs might be reconceived in ways that are deliberately inclusive. What if we were to premise education upon greater flexibility? What if we were to strike from our conceptual repertoire outdated notions such as the *undifferentiated graduate*? If we were to shift the structures of education from the perspective of disability, we would create pressure to change the next stages: residency, employment, and healthcare systems. We have seen this through the advancements made thus far that are products of the pressure created by the “Americans with Disabilities Act (ADA) generation” and those leaders who came before and their rightful sense of entitlement to a better world.

Alison Kafer (2013) argues for a politics of *crip futurity* through which we imagine disability and disabled people’s lived presents and possible futures differently. To do so, she says, we must challenge the rhetoric of naturalness and inevitability that currently dominates perceptions of societal barriers to inclusion (Kafer, 2013). This requires us to assert that decisions about the futures of disability and disabled people are political (Kafer, 2013). In that way, we must look at the barriers students currently experience in health science education, and rather than taking them for granted, we must see them as political. We must ask, what causes these barriers to seem natural and inevitable? How might this situation be changed? What might a future that assumes disabled health professionals are natural and inevitable look like? What could health science education look like if it started from a place of valuing disability and the ways of being in and knowing the world that comes with it?

In closing, I ask us all to consider whether we dare to dream of a different future. How much longer are we willing to wait for real change to come? Let us dream together toward transformation, moving toward a world we want to see; a world we all need.

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