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Public Scholarship as Disability Justice

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We each become the protagonists of our stories of change and transformation.
—Judithe Registre (2018)

Public scholarship is, quite simply, scholarship for the public. It appears as different forms of engagement—blogs, social media posts, vlogs, websites, podcasts, museums, documentaries, op-eds, lectures, essays, activism, exhibits, television, and so on—and is predicated on making knowledge accessible to the public. It bridges academic expertise with public consciousness, circulating in spaces that are easily understood and available to address publicly identified needs. Public scholarship has always existed, but it has become an integral aspect of academic discourse over the past twenty-five years as researchers build relationships with their communities through social justice (Leavy 2019; Badgett 2015; Dodd and Garland-Thomson, 2013; Nightingale 2013; Gonzales 2019; Cann and DeMeulenaere 2020). As Adrianna Kezar, Yianna Drivalas, and Joseph Kitchen emphasize, "Public scholarship is connected and closely related to the words *diverse democracy*, *equity*, and *social justice*" (2018, 4).

If public scholarship is centrally about making knowledge accessible, then what does it mean for it to act as disability justice? That is, if justice is the "first virtue of social institutions," as philosopher John Rawls (1999 [1971], 3) declared, then how do we continuously ensure that disabled people, their lives, and their histories are represented in spaces that are made accessible to them? How can academics researching and writing about disability history democratically engage with disabled communities? Public history, a subset of public scholarship, affords such an opportunity: as citizens and scholars, historians possess responsibility for disseminating knowledge, clarifying past narratives and concepts, and preserving primary sources and factual analysis (Cauvin 2016). Digital spaces have especially provided tools for reaching a wider range of audiences, including those—such as disabled people—who tend to be excluded from academic institutions or restricted from obtaining historical resources on account of inaccessibility.[1] Moreover, the historical marginalization and silence, if not absence, of disabled people in the archive has prompted scholars to rethink "the archive" itself and how historical materials are collected and categorized. "Cripping the archive" not only prompts a critical reexamination of how ableness informs the politics of archives, it also presents multiple perspectives for evaluating the temporal, spatial, and material constructions of disability.[2]

Public scholarship, then, allows us to reimagine our audience and assumptions about what counts as "academic" scholarship. When I was a graduate student, I launched a blog to share aspects of my research on nineteenth-century cultural histories of deafness and medicine. Promoting the blog required cross-posting on social media, not just the posts but also interesting tidbits I learned while browsing digitized collections for materials or searching for related historical images. As I tracked the engagements and blog statistics, I learned that most followers of my content were not academics—as I believed—but curious general readers, some of whom were deaf and eager to learn about their shared medical past. This forced me to confront my own assumptions about how academic scholarship can exclude the very people whose histories are being examined and exposed.

Sharing images with brief context soon became a form of engagement, a way to educate the public on historical aspects of diseases, vaccination, medical advancements, and cultural frameworks of health and healing. As with all forms of curation, this also became an ethical process. While some historical images can be fun and quirky, or informative, others require more nuanced and sensitive oversight to avoid being sensationalized or decontextualized. This becomes more crucial when we address the implications of *looking* at pictures of people's suffering and diseased bodies: Do we learn anything more? Is it appropriate? Is it meant to shock or discomfort the viewer?

Suzannah Biernoff (2017) has addressed the troubling liaison between medicine and art, focusing on photographs of plastic surgeon Harold Gillies's World War I patients with severe facial injuries. With the images in the public domain, Biernoff questions what the new frontiers of visuality will be when they are appropriated for public consumption without historical context. Medical images especially tend to become "an ethical borderland in which legal definitions of privacy, personhood, and human rights compete with the contemporary politics of witnessing, memory, and memorialization; a space of fantasy where fascination and aversion are found in equal measure" (Biernoff 2017, 169).

"What do we gain for seeing images like these?" Biernoff (2012, 187) asks. What do we gain by viewing suffering, especially when perceived through a medicalized gaze? And how do we, as historians, connect objectivity and historical value with the tendency for sentimentality and spectacle, which can become problematic? I confess that I, too, have made errors in judgment when sharing shocking images of medical injuries or disfigured bodies, unaware of how they could be read differently. These are images that can be fascinating and appealing to the medically curious, but they also continue to propagate freakery, a concept that has long served to diminish the value of disabled people.

We nevertheless still stare in astonishment, sustaining our gaze—sometimes in wonderment, other times in befuddlement. Staring, as Rosemarie Garland Thomson explains, is a "vivid form of human communication," one that is "an embodied and relational visual exchange that carries complex cultural and historical meanings" (2005, n.p). Nowhere is this embodiment so vivid as in discussions of disabled, disfigured, or deformed bodies, the histories of people whose perceived abnormality invited the medical gaze. But in the process of creating, viewing, categorizing, and exhibiting a "freak"—even if it offers academics avenues for theorizing how disability fits within medical history—we strip disabled people of control over their own narratives. We remove their agency, reduce their personhood to mere object of curiosity, and erase their lived experiences.

What happens, then, when we return autonomy to disabled people and center their stories? That is what disabled activist Alice Wong set out to do with the Disability Visibility Project (DVP), which launched in 2014 in partnership with StoryCorps. An online community dedicated to creating, sharing, and amplifying disability media and culture, DVP is written by disabled people, based on the notion that "disabled narratives matter and that they belong to us" (Disability Visibility Project, 2021).[3] Championing disability culture, history, art, media, and politics, DVP organizes and facilitates events and work by disabled people through blog posts by guest writers, oral history interviews, and social media promotion and hashtags. In 2017 DVP expanded to include a podcast, and an anthology, *Disability Visibility: First-Person Stories from the Twenty-First Century*, was published in 2020 (Wong 2020). The podcast was archived following its 100th episode in April 2021.

Wong's achievements in publicizing DVP demonstrate how narratives are crucial in the formation of identity creation and transformation, particularly for justice-based activism and politics. As David Engel and Frank Munger argue, "Perceptions of who one is and where one belongs in relation to others play a critical role in determining whether rights are understood as relevant" (2007, 86). Using life-story narratives becomes a powerful approach for conveying how individual experiences of disability can construct meaningful understandings for policy, such as how American disabled activists used their narratives—and especially bodies—to show the public how social and environmental barriers prevented their full inclusion into society and eventually led to the passage of the Americans with Disabilities Act (ADA) in 1990 (Pelka, 2012). These narratives add to the richness of our collective cultural heritage, but the struggles were not erased the moment that the ADA was signed into law. The "ADA Generation," a term coined by disability activist Rebecca Cokley, defines the first generation of disabled advocates who grew up at the intersections of disability rights legislation, "expecting its rights but also [finding] resentment instead—propelling a need to keep pushing back" (Shaprio, 2020). They are the people who work to "bend the arc of justice into a ramp" (Cokley, 2018). For them, disability is identity and pride. For disabled people of color like Wong, moreover, narratives position them in cultural discourses in which they have long been left on the sidelines (Wong, 2015).

Judithe Registre (2018) proclaims that narrative justice is a new era of advocacy, one that forms "the creation of a cultural awakening that seeks to shift representation, voice, and agency." Redefining the gatekeepers of scholarly knowledge and making space for the marginalized who have long been shunned from avenues of power enables us to dismantle existing power structures and social inequities. This includes citational justice, which acknowledges the inequities and power imbalances in the way work is credited and appropriated as a resistance to unethical hierarchies of knowledge production (#CiteBlackWomen is an example).[4] For we cannot achieve social justice when people are silenced: "Their own experiences and stories are never allowed to speak, never fully understood to self and others, and never connected with others to form allies and solidarity for social justice" (Lee and Johnstone 2021, 725). Narratives, then, lay the groundwork for justice. They use the power of the word enriched with emotion—written, spoken, articulated—to shape the necessary change for justice by cultivating resistance to oppression.[5]

For disability advocacy more specifically, narrative justice can serve as a form of affirmation: it ensures that disability narratives and disabled people are not erased in stories about them, and it presents their lived experiences as celebratory joy and individual experience, rather than the usual tale of trauma and overcoming. Moreover, it is imperative that these stories are made accessible to disabled people as well—these are *their* as well as *our* histories and experiences, after all, and providing access serves to both inform and confirm these narratives. Anthology collections like *Disability Visibility*, *About Us* (Catapano and Garland-Thomson, 2019), and *Resistance and Hope* (Wong, 2018) further outline the variability of human experience and the value of learning from disabled people themselves—echoing the community's long-standing slogan, "Nothing about us without us." And I believe narrative justice through essay writing becomes all the more crucial for addressing misinformation or for contextualizing social issues that could benefit from a disability perspective.

It is at this juncture that a bridge is needed between academic scholarship and public history: by making theoretical and historical writing accessible for general readers, we can dismantle barriers that prevent disabled people from accessing knowledge about their social, cultural, and political histories. Several institutional initiatives have achieved this with exhibitions on disability histories: Ryerson University's traveling exhibit *Out from Under: Disability, History, and Things to Remember*; Nineteenth-Century Disability: Cultures & Contexts, an online primary source repository; and the Disability History Museum, a virtual project with over three thousand primary sources, as well as exhibits in traditional brick-and-mortar museums such as the Smithsonian National Museum of

American History's *EveryBody: An Artefact History of Disability* (Virdi, 2020).[6] Yet as evident with DVP and the growth of public scholarship, public history has outgrown its traditional associations with museums and journalism, especially given issues of inaccessibility arising from physical and institutional barriers.[7]

That is, public history goes beyond simply writing or creating exhibits for a public audience. It demonstrates the past matters as more than historical memory—it is a tool for explaining how and why our societies are the way they are, and for better understanding the structural inequities that commemorate the "victors" and distort the experiences of the colonized and oppressed. Or, as Robert Kelly explains in his classic essay, the historian's perceptive is crucial, for "the historian has a special way of looking at human affairs, and a special way of explaining them" (1978, 16). As a historian of medicine and disability with a prominent social media platform, I especially feel the burden to address issues of public health, vaccination, ableism, and medical racism, issues that are structurally imbedded in our society and regularly used to convey misinformation. Yet I believe that historians—all specialists, but especially those studying disability history—have a responsibility to ensure their work is accessible outside the academy.

Public scholarship, then, can act as a form of activism for disability justice. Through Wong, I learned of Tressie McMillan Cottom's assertion that "the best essays build a public thought process and form," by which essay writing becomes an activist tool (Wong, 2022, xv).[8] For example, in February 2021, Nike announced its "hands-free" Go FlyEase sneaker, which was quickly praised for its accessibility features. Observing that the initial announcement failed to acknowledge the history of the FlyEase's collaboration with disabled people, I posted a tweet identifying the need to acknowledge and celebrate disability design, a point that I regularly incorporate in my own scholarship and teaching.[9] The tweet went viral, with 18.5 million impressions, but the responses nevertheless still failed to address that a shoe that was clearly designed for disabled people ended up erasing their participation. In partnership with disabled advocate and designer Liz Jackson, I wrote an essay for *Future+Tense* (a subsidiary of *Slate*) emphasizing the importance of marketing products to disabled people beyond tokenistic representation or inspiration. "And if we've learned one thing as disabled design critics," we emphasized, "it is that stories inform the way we design" (Virdi and Jackson, 2021).[10]

Jackson and I created an important discourse with our essay: marketing products to disabled consumers while erasing them is not a new phenomenon or entirely Nike's fault but rather part of a legacy of capitalism that tends to undervalue disabled people's full participation and inclusion in society. Positioning disabled people at the center of their own narratives—or better, making space for them to tell their own stories—affords us perspectives for better understanding the spectrum of human experience, especially that of disabled people of color and colonized people whose places in history have been written over, if not completely ignored.

Public scholarship, and public history, provides us with powerful tools to demonstrate the ways disability history matters. It reaches beyond the academy to the public directly, informs equitable museum and archive practices, intervenes into design process, and above all demonstrates the importance of representation. It is important for academic writing to be accessible to the people who are being written about, and moreover, as historians, we have a responsibility—perhaps now more than ever—to explain our collective past and clarify concepts. With public history, we can better understand the world we live in and incorporate a diversity of perspectives in order to create a more just and inclusive vision for ourselves, what Alison Kafer (2013, 24) terms "crip futurity": a longing for a future in which the collective knowledge and practices of disabled people shape all aspects of society.

NOTES

1 Angela Gallagher, "Archives and the Road to Accessibility," *Perspectives on History* (15 July 2019).

2 The concept of "Cripping the Archive" is the subject of Jenifer Barclay and Stefanie Hunt-Kennedy's forthcoming edited collection, *Cripping the Archive: Disability, Power, and History*.

3 Disability Visibility Project, "About." accessed August 30, 2021. https://disabilityvisibilityproject.com/about/ .

4 Diana Kwon, "The Rise of Citational Justice: How Scholars are Making References Fairer," *Nature* (22 March 2022).

5 Geeta Tewari, "Regarding Narrative Justice, Womxn," *Michigan Journal of Race and Law* 25 (2019): 61–75; Rafe McGregor, *Narrative Justice* (London: Rowman and Littlefield International, 2018).

6 *Out From Under* (www.ryerson.ca/ofu); *Nineteenth-Century Disability* (www.nineteenthcenturydisability.org); *Disability History Museum* (www.disabilitymuseum.org); *EveryBody* (www.everybody.si.edu). For more on digital exhibits and disability history, see: Jaipreet Virdi, "Materializing User Identities & Digital Humanities," in *Making Disability Modern: Design Histories*, Bess Williamson and Elizabeth Guffey editors (New York, NY: Bloomsbury, 2020), 225–241.

7 Alex Marshall, "Is this the World's Most Accessible Museum?" *New York Times.* September 11, 2019.

8 Tressie McMillian Cottom, "Why I am Building This Community," essaying (24 February 2021).

9 Jaipreet Virdi, "Disability Design for the Win!" Twitter Post, 1 February 2021, 3:02 pm. https://twitter.com/jaivirdi/status/1356332028212477952?s=20.

10 Jaipreet Virdi and Liz Jackson, "Why Won't Nike Use the Word Disabled to Promote Its New Go FlyEase Shoe?" Slate/Future Tense, 5February 5, 2021. The essay received over 115,000 page views. Our warning that the sneaker would be financially inaccessible for the consumers that need them the most realized a few months later as the initial limited release sold out and the once-priced at $120 sneakers were being listed online for upwards of $2,000. Despite criticism, as of October 2021, Nike has still not listed the new Go FlyEase on its website.

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