Foreword

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Disabled people are doing amazing things in the twenty-first century, much of it built on the wisdom of our disabled ancestors. However, disabled people are still silenced, hidden, stigmatized, and dehumanized all over the world. We face continued assaults on our personhood and bodily autonomy at the systemic and interpersonal level. Ableism, coupled with white supremacy and other forms of oppression, seeks to erase and eliminate us. For example, germline human gene editing may one day "fix" an embryo and remove genes that cause disability in the name of preventing suffering. Germline modification is alarming because it would change the genes in eggs, sperm, or early embryos by using CRISPR, a gene editing tool that became popular because it's fast, cheap, and accurate[1]. This means subsequent generations would also carry those changes with unknown consequences. Excitement around the science and possibilities of eliminating disease outweigh any questions about the underlying assumptions about health, disability, and dif-

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[1] Center for Genetics and Society, "What is Human Gene Editing?" (n.d.), https://www.geneticsandsociety.org/internal-content/what-human-gene-editing.

ference.[2] The idea of giving babies an advantage whether it's less likelihood of developing a disease or enhancing other traits is irresistible to people with the means to give their kids quote unquote "the best."[3] The best, meaning a life without a disability, such as people with neuromuscular disabilities like me.

Eugenics is not a relic of the past. The state and other institutions have been trying to eliminate us for centuries. The eugenics movement sought to prevent some people with mental illness or physical disabilities from being able to have children.[4] California had the nation's largest forced sterilization program, sterilizing about 20,000 people beginning in 1909 and the program didn't end until 1979.[5] Many of the women sterilized were incarcerated or Black, Latinx, Indigenous and disabled women. Up to the 2010s, a disproportionate number of disabled BIPOC people were still being sterilized without their consent in California's prisons

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[2] Rebecca Cokley, "Please Don't Edit Me Out," *The Washington Post*, August 10, 2017, https://www.washingtonpost.com/opinions/if-we-start-editing-genes-people-like-me-might-not-exist/2017/08/10/e9adf206-7d27-11e7-a669-b400c5c7e1cc_story.html.

[3] Wong, Alice. "Message From the Future: Disabled Oracle Society," *Disability Visibility Project*, August 14, 2020, https://disabilityvisibilityproject.com/2020/08/14/message-from-the-future-disabled-oracle-society/.

[4] Smith, Leah, "An Attempt at Reparations: California's Forced or Involuntary Sterilization Program," *The National Center for Disability, Equity, and Intersectionality*, March 14, 2023, https://thinkequitable.com/an-attempt-at-reparations/.

[5] Associated Press. "California Tries to Find 600 Victims of Forced Sterilization for Reparations," *The Guardian*, January 5, 2023, https://www.theguardian.com/us-news/2023/jan/05/california-reparations-forced-sterilization.

and mental health institutions, despite this having been illegal since 1979.[6]

Recently, disabled people in Canada protested the passage of a medical aid in dying bill that expanded the criteria on who was eligible including people with a range of disabilities who are not terminally ill. Disabled Canadians wrote op-eds, testified to their local governments, and organized online to get the public to understand how easily this can be abused and used to coerce people who are living in poverty or not getting the supports they need into thinking they have no other choice.[7] Unfortunately, this bill passed but the government announced in early 2023 a temporary exclusion of medical aid in dying for people with the sole criteria of having a mental illness.[8] Can you believe in Canada it could become completely legal for any person with a mental illness to be killed by a doctor?

There are many existential threats all over the world. With prenatal screening, countries like Iceland and Netherlands have an almost 100 percent abortion rate for fetuses with

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[6] Shilpa Jindia, “Belly of the Beast: California’s Dark History of Forced Sterilization,” *The Guardian*, June 30, 2020, https://www.theguardian.com/us-news/2020/jun/30/california-prisons-forced-sterilizations-belly-beast.

[7] James Wilt, “Fillibustering Death-Dealing Ableism,” *Canadian Dimension*, June 2, 2022, https://canadiandimension.com/articles/view/filibustering-death-dealing-ableism.

[8] Government of Canada. “Medical Assistance in Dying,” March 27, 2023, https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html.

Down syndrome.[9] A letter published in a Dutch national newspaper in 2017 stated that the freedom to birth disabled children should be limited by the "financial burden" to society.[10] And this is intentional by the state as some countries are increasingly opting for a targeted approach which means commercial companies, health authorities and policymakers are targeting specific genetic conditions while prohibiting the prenatal selection of other groups. The Netherlands singled out Down syndrome as the primary target of its national screening program.[11] It is the first country in the world that offers noninvasive prenatal testing, unsolicited, to all pregnant women. It is quite possible in several generations that people with Down syndrome may disappear altogether in certain countries.

Disabled people are up against so many structural and societal pressures making it almost impossible to survive in a nondisabled world. I feel despair when I witness such systemic violence and ableism and yet I see everyday how disabled brilliance is changing the world whether the world recognizes it or not. And this is why archival work is so important. As a storyteller, there's an undercurrent pulling me constantly and reminding me I am in a race against time.

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[9] Julian Quinones and Arijeta Lajka, "What Kind of Society Do You Want to Live In?: Inside the Country Where Down Syndrome Is Disappearing," *CBS News,* August 15, 2017, https://www.cbsnews.com/news/down-syndrome-iceland/.

[10] Renate Lindeman, "A Moral Duty to Abort," *Huffington Post*, September 21, 2017, https://www.huffpost.com/entry/a-moral-duty-to-abort_b_59c3a01ae4b0ffc2dedb5b3c.

[11] Sarah Zhang, "The Last Children of Down Syndrome," *The Atlantic*, December 2020, https://www.theatlantic.com/magazine/archive/2020/12/the-last-children-of-down-syndrome/616928/.

Leaving something behind is an act of defiance and preservation. Collections such as the Eugenics Archives[12], a collaboration of scholars, survivors, students, and community partners in challenging eugenics in Canada that features stories of eugenics survivors, Deaf South Asian Stories recorded by radio producer and storyteller Sarika D. Metha housed at the South Asian American Digital Archive[13], and the Disability Visibility Project[14], an oral history campaign in partnership with StoryCorps, are pockets of stories that form a constellation of disabled lives and cultures.

Who gets to be an archivist? This is a question I wrestle with often. Internalized ableism and structural and access barriers kept me from identifying as a writer and activist for a long time. It took me many years to be able to claim those roles and while the heart of my work has been curatorial and archival, I still hesitate identifying as an archivist. Disabled people are scholars and archivists whether they use those terms or not. Our contributions may be informal and not considered as "legitimate" but they are valuable and valid because they are stories for us and by us. No university, library, or archive can take that away from us.

The Disability Visibility Project (DVP) is an online community dedicated to creating, sharing, and amplifying disability media and culture. When I started in 2014 it was initially a small community partnership with StoryCorps, an oral his-

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[12] Eugenics Archives, (n.d.), https://eugenicsarchive.ca/.

[13] South Asian American Digital Archive, (n.d.), https://www.saada.org/browse/language/american-sign-language-asl.

[14] Disability Visibility Project, (n.d.), https://disabilityvisibilityproject.com/about/.

tory organization. As a number of disability rights nonprofits and activists geared up for the 25th anniversary of the Americans with Disabilities Act (ADA) the following year, I wondered what I could do as an individual. I was frustrated that our histories and stories are not taught in schools. Stereotypes and tropes abound in current depictions and reporting on disability such as stories of overcoming or othering. Rarely are disabled people the producers of their own stories in conversation with other disabled people. This is why, over thirty years after the ADA, portrayals of disability still depict disability as a burden, a terminal illness, a fate worse than death, an inspiration, or something that needs to be eradicated.

By centering the lived experiences of disabled people and giving them access to tell their own stories on their own terms, the Disability Visibility Project celebrates the abundance of disabled people. Participants in the DVP oral history campaign have the option of having their story archived at the Library of Congress. I don't have the infrastructure or access to do something like this as a single person but I leveraged what StoryCorps offered to create a collection that will exist forever and available to the public. There is power in carving out spaces like this. Through our stories, I hope that people understand how disability can be a generative source of creativity and innovation, a radical way of thinking about the world and how to live in it.

I have no background in LIS or archival studies but I know that building an archive is about structure and how these structures come with cultures, politics, and memories that leave evidence at an institutional level. Unintentionally, I became a de facto community archivist and made an indelible impact on StoryCorps' practices and policies. The DVP is the longest sustained partnership in StoryCorps' history with approximately 140 oral histories from the disability community. Because of the high participation rate and presence of disabled people, StoryCorps changed in the following ways:

- Staff at the San Francisco location (no longer in operation) changed their protocols and practices to increase accessibility and move from a model of accommodations to access intimacy (e.g., reminder calls asked about accessibility needs, option of verbal / visual / touch time cues, placing mic at speaker's mouth and at assistive speech device, etc).

- The organization created Braille introduction cards in partnership with the San Francisco Public Library and the Library for the Blind and Print Disabled and additional Braille cards were generated to other StoryCorps locations. They also created data sheets and release forms with several large print options in varying font sizes.

- A staff member created an audio tour of the booth with audio, video, and captioning[15]

- San Francisco's StoryCorps staff included accessibility learning and best practices in their training with all community partners. They distributed a survey in 2015 asking for participant feedback on accessibility.[16]

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15 Yosmay d, "SF StoryCorps Audio Tour," November 18, 2015, YouTube video, 6:40 https://www.youtube.com/watch?v=SyeNnVcZpZw

16 Alice Wong, "StoryCorps Accessibility Survey: Please Participate!", *Disability Visibility Project*, May 29, 2015, https://disabilityvisibilityproject.com/2015/05/29/storycorps-accessibility-survey-please-participate/.

- Accessibility emerged as the number one strategic priority of the organization as identified in the all-staff retreat in 2015. StoryCorps created an internal Accessibility Project Team in 2016 with staff from multiple departments tasked with creating official recommendations and protocols for improving organizational accessibility.

- The Recording and Archive team did an accessibility audit for all the booths & mobile ensuring wheelchair access and which also culminated in a newly designed folding table and ceiling mount mic system, and signature guides for all venues.

- The DVP influenced the decision to pilot a 10-interview Smithsonian Institute and Kennedy Center in Washington DC with video recorded interviews from the D/deaf community. This partnership required planning not only for interpretation and facilitator set up, but also collaboration with the Library of Congress staff on how to store and edit each interview.

One does not need to have a graduate degree to be an archivist. One does not need training in research methods or receive IRB approval to be an archivist. One does not need a grant or be affiliated with an academic institution to be an archivist.

My intention in sharing the history of the DVP isn't to humblebrag; instead, it's to show how curiosity and care can spark any person to become an archivist. Having a love for community and a commitment to preserving our culture can form the foundation for any disabled archivist. And this is why *Preserving Disability* is such a significant publication. Edited by Drs. Gracen Brilmyer and Lydia Tang, this book offers disabled perspectives in stories and case studies by disabled archivists, scholars, and archive users. Unlike other academic texts, there is no distinction made between professionals and non-professionals. Together, we conjure the past, present, and future. We create, collaborate, dream, and imagine what is possible and what is needed. We honor the wisdom of our ancestors as we preserve our knowledge, culture, and stories for successive generations.

The precarious nature of being disabled can be isolating and bleak. Like many other disabled people, my life hangs by a thread as I almost died during a four-week hospitalization in 2022 and struggled to remain in the community due to the high cost of private-pay caregivers that I need to supplement the services I receive from the state. And still, I tell my story and amplify the stories of others with a sense of urgency that accelerated ever since I founded the DVP. I do not know what the future holds for me personally, but I am not alone. Knowing that collections created, used, and maintained by disabled people are connected to one another in a crip mycelial network, I am filled with gratitude for being alive in this time and the relationships that keep me tethered to this luminous disabled universe.