

# Disability History Association News

Fall, 2020

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## Editorial

The year 2020, not yet over, is already assured a place in history as being eventful.

The Covid-19 pandemic has touched us all in some way or other. From a DHA perspective, we were saddened to learn that one of the Association's longstanding members, Brian R Miller, contracted Covid and did not survive – Kim Nielsen pays tribute to Brian in this edition. It has been acknowledged that certain groups of people have experienced particular vulnerability to contracting Covid, yet have also attracted poor consideration for support as some governments focus disproportionately on economic fall-out over people's care, cure and survival. It has therefore been a time of special concern and stress for people with a disability or with a variety of health conditions. While the impact of Covid is ongoing, this Fall 2020 DHA News is delighted to present the reflections of three scholars on Covid and Disability. This international selection of essays comes from Jessica Dimke in Norway, David Kilgannon in Ireland, and Nancy Hansen in Canada.

In the USA especially, but also across the world, the killing of George Floyd ignited an issue that has been simmering for decades and gave birth to the Black Lives Matter movement. The Disability History Association has embraced these efforts to

bring about true equality in society and the Board issued a statement in June, not just to express abhorrence at recent and historical events, but to address ways in which DHA can pursue its own affirmative action. The DHA statement is repeated in this edition.

We are pleased to announce the winners of the DHA's Public History Award and the latest Journal Article / Book Chapter Award. Congratulations to our awardees. A decision was taken to delay the DHA Book Award adjudication since Covid resulted in many book publishers having to operate under abnormal circumstances while postal slow-downs have also occurred, this disrupting provision of books to the award adjudicators. However, on a more positive note, the DHA intern programme continues unimpeded, Kirsten Nassif of the University of Delaware has recently begun her internship for 2020/1, and 2019/20 intern, Jinseul Jun, recounts her experiences as she moves on to new adventures.

If you enjoy this edition, or even if you don't, please consider writing something for the Spring 2021 issue – we would really like to know what you are all researching, discovering, writing, publishing, presenting ...

Iain Hutchison

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## The Disability History Association's Statement on Anti-Racism.

The murders of George Floyd, Ahmad Aubrey, and Breonna Taylor have sparked a firestorm of collective grief, anger, and protests against structural racism and the resulting systematic oppression and widespread violence. The Disability History Association (DHA) stands in solidarity with anti-racism activists and their fight for racial justice. We affirm that Black Lives Matter.

Our response to this moment demands a complex approach that is committed to both anti-ableist racial justice and anti-racist disability justice.

The rallying cry of the anti-racism movement, *I can't breathe*—also the last words of too many Black people dying at the hands of police—emphasizes the ways Black disabled people's health and well-being are disproportionately affected by white supremacy and social and environmental injustice. Chronic illnesses such as asthma, hypertension, and diabetes disproportionately affect Black communities. Systemic racism has created healthcare disparities through discriminatory diagnosis, institutional barriers, and lack of access. Structural segregation has also ensured that Black people are more likely to live in food deserts, areas without clean water or

air, and high-poverty areas without access to green spaces. Moreover, Black adults often work in low-paying frontline jobs that expose them to greater occupational hazards and, thus, chronic illnesses or disabilities. Black disabled people also encounter law enforcement officials—including for welfare checks or during a mental health crisis—at disproportionately higher rates.

According to the National Disability Institute, fourteen percent of working-age Black people have a disability compared to Non-Hispanic Whites (11 percent) and Latinxs (8 percent). Furthermore, because both disability and race are determinants of socioeconomic inequality, Black disabled people remain one of the most vulnerable groups. Having a disability is costly, and ableism itself can severely limit disabled people's economic opportunities. In the United States, to obtain disability benefits and health coverage, an individual has to prove they are incapable of work; at the same time, welfare programs require applicants to be employed, forcing disabled people to make difficult financial choices. These material realities can further exacerbate chronic conditions and delay/restrict necessary treatment and support. We have seen, time and again, the tragic results of these intersections.

The DHA recognizes the entanglement of racism and ableism, and that a multiplicity of historical processes created these conditions. We are aware of the ways that Black communities and Black disabled people have been targeted by the violent, racist, and ableist systems of white supremacy, in both the past and in the present. The legacies of U.S. racial chattel slavery remained entrenched in local policies, state laws, and federal legal decisions. They remained entrenched, as well, in the U.S. Constitution. Merged with eugenics, which gained remarkable popularity between the American Civil War and World War II, these oppressive forces have systematically targeted Black disabled people for institutionalization, immobilization, and violent interventions. Cases like those of Junius Wilson, a deaf man incarcerated in the Jim Crow South for a crime he did not commit, were not uncommon. After the Second World War, eugenics persisted in old and new forms. Eugenic philosophies and practices permeated debates about genetic counseling, public education, and the provision of healthcare, perpetuating the constitutive claim that white, able-bodied people were superior to Black and Black disabled people.

The impacts of these racist and ableist projects persist into our current moment. As a lethal and disabling pandemic grips the world, disability and Black communities across the United States have been disproportionately impacted by COVID-19. The deadly combination of systemic racial injustices, spatial and economic discrimination, lack of equitable access to healthcare, and institutionalized ableism have proven especially dangerous for Black and disabled people. Not only are Black people more likely to be hospitalized for COVID-19, they are much more likely to die from COVID-19 than any other group. In New York, for instance, the COVID-19 death rate for Black populations was as high as 92.3 per 100,000 population, which is substantially higher than death rates for Hispanic/Latinx (74.3/100,000), white (45.2) or Asian (34.5) populations. Meanwhile, disabled people—Black and otherwise—have faced shortages of life-sustaining medications, been targeted for abandonment through resource scarcity protocols, and had do-no-resuscitate orders (DNRs) issued without their consent. There is also growing evidence that people who survive coronavirus

may also have long-term disabilities, which are also likely to have disproportionate impacts on the Black community.

Despite these historically consequential connections between racism and ableism, Black disabled people's stories have been erased from the annals of history. As activist Vilissa Thompson has asserted, without Black disability history, the political and societal developments that many of us take for granted might not have occurred. We need to spotlight histories of prominent Black disabled figures — such as Harriet Tubman, Fannie Lou Hamer, and Mary Church Terrell — and also acknowledge the roles many Black disabled people have occupied in the pursuit of justice. Members of the Black Panther Party not only aided disabled activists during the 504 sit-in protests, but also created networks of healthcare centers and food programs to address the disabling effects of medical and educational racism. Black and Latinx activists contributed significantly to twentieth-century efforts toward deinstitutionalization. And Black, disabled activists have been at the frontlines of American Disabled for Attendant Programs Today (ADAPT).

The DHA promotes the study of disabilities throughout history. We are committed to advancing Black membership and leadership within the DHA, and to cultivating partnerships with Black institutions and organizations. Our mission is to foster various perspectives, representations, and policies on disability, including the ways that disability and race are intertwined. We commit ourselves to anti-racism and the dismantling of white supremacy by:

1. **Critically reflecting on the DHA's practices in order to identify the ways in which it participates or is complicit in the racist and ableist structures of higher education.** This includes an examination of how we can dismantle implicit bias and systemic oppression in practices and uphold the DHA's mission and anti-racist, anti-ableist stance.
2. **Supporting, promoting, and amplifying historical work by Black and Black disabled people.** We also strive to promote the documentation and dissemination of information about the history of Black disabled experiences, the intersection of racism and ableism, and Black disabled activism and resistance. We will continue to use our social media to elevate Black creators' hashtag campaigns, including #BlackDisabilityHistory and #BlackDisabledLivesMatter.
3. **Supporting, promoting, and amplifying research into the historical intersections of race and disability, as well as the intersections between past and present experiences of being Black and disabled.** We will continue to use our blog, *All of Us*, to encourage conversations about the connections between past and present Black disabled histories.
4. **Seeking diverse leadership, membership, and partnership in our organization.** We commit to actively striving to recruit BIPOC historians of disability to join the DHA and to positions of leadership within the DHA. We also commit to inviting BIPOC historians to be interviewed for our podcast series, submit articles to our blog, and apply for our awards.

### Readings on Disability & Race

Christopher M. Bell (ed.), *Blackness and Disability: Critical Examinations and Cultural Interventions*. East Lansing: Michigan State University Press, 2011.

Liat Ben-Moshe and Sandy Magaña, "An Introduction to Race, Gender, and Disability: Intersectionality, Disability Studies, and Families of Color," *Women, Gender, and Families of Color* 2.2. (Fall 2014): 105-114.

Susan Burch and Hannah Joyner, *Unspeakable: The Story of Junius Wilson*. Chapel Hill: University of North Carolina Press, 2007.

Chris Chapman, Allison C. Carey, and Liat Ben-Moshe, eds., *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*. New York: Palgrave, 2014.

Arida Imada, "A Decolonial Disability Studies?" *Disability Studies Quarterly* 37.3 (August 2017).

Angel L. Miles, Akemi Nishida, Anjali J. Frober-Pratt, "An Open Letter to White Disability Studies and Ableist Institutions of Higher Education," *Disability Studies Quarterly* 37.3 (August 2017).

Therí A. Pickens, "Blue Blackness, Black Blueness: Making Sense of Blackness and Disability," *African American Review* 50.2 (Summer 2017): 93-103.

Ellen Samuels, *Fantasies of Identification: Disability, Gender, Race*. New York: New York University Press, 2014.

Jorge Matos Valldejuli, "The Racialized History of Disability Activism from the 'Willowbrooks of this World,'" *Activist History Review*, Oct. 2019

### Resources on Disability & Race

Museum of Disability History virtual exhibit on disability & the African American experience: <https://www.museumofdisability.org/disability-and-the-african-american-experience/>

"An Open Letter to the Disability Community on Why Black Lives Matter and Allyship" letter to disability groups about Black Lives Matter

"Ramp Your Voice!" "an organization dedicated to issues of race and disability Rooted in Rights, "Race and Disability"

Institutionalized Racism: A Syllabus

Crowdsourced Disability Studies Readings on the Intersections of Disability & Race National Disability Institute, *Financial Inequality: Disability, Race, and Poverty in America* (2019).

Centers for Disease Control & Prevention, "COVID-19 in Racial and Ethnic Minority Groups" (2020).

Where to donate: <https://www.nylon.com/life/black-people-with-disabilities-donations-resources>

[This statement was released on June 17, 2020.]

## Brian R. Miller (1967-2020)

An Appreciation by Kim Nielsen



The DHA lost a valued member when Dr Brian R. Miller died on April 13, 2020.

Miller received his PhD from the University of Iowa in 2013 where he worked with Dr Douglas Baynton. In his dissertation, “Speaking for themselves: The blind civil rights movement and the battle for the Iowa Braille School”, Miller chronicled the efforts of blind activists whom he argued were “determined to implement a new philosophy of blindness against what they perceived to be the entrenched power of sighted rehabilitation and education professionals”.

Fortified with a historical understanding of advocacy and civil rights, and his own experiences of discrimination as a blind student, Miller advocated for disabled students in his position at the U.S. Education Department’s Rehabilitation Services Administration. The historian, activist, musician, and world traveler valued historical knowledge and education as means to create futures.

He loved *The Who*, was willing to try nearly any food when travelling, took what he called “blind guy” photos to post on Facebook, and had a marvelous singing voice.

*The Washington Post’s* memorialization of Miller can be read at:

<https://www.washingtonpost.com/local/education/brian-miller-whose-blindness->

[inspired-a-career-helping-disabled-students-dies-of-covid-19/2020/04/14/36693a36-7e67-11ea-8013-1b6da0e4a2b7\\_story.html](https://www.inspired-a-career-helping-disabled-students-dies-of-covid-19/2020/04/14/36693a36-7e67-11ea-8013-1b6da0e4a2b7_story.html)

(Image: Flanked by Tasing Chiu, Department of Medical Sociology and Social Work, Kaohsiung Medical University, and Kathy Kudlick, Paul K Longmore Institute on Disability, San Francisco State University, Brian relaxes after dinner during a conference titled *The History of Blindness and the Blind: Representations, Institutions, Archives: An International Perspective*, Paris, June 2013. Credit: Kim Nielsen)

## Welcome Wayne and Miles

DHA welcomed two new Board members this summer. They are Wei Yu Wayne Tan, an Assistant Professor in History at Hope College, and Miles McKinley Wilkerson of University of Wisconsin-Madison who joins the DHA Board as graduate representative.

Wayne received a Ph.D. in Japanese history from Harvard University in 2015. He was an Andrew W. Mellon Postdoctoral Fellow in the Humanities at Dartmouth College (2015-2016) and is currently an Assistant Professor of History at Hope College. He is revising his book manuscript, which explores the social and cultural history of blindness in Japan to provide comparative historical perspectives on disability. His research has been published in edited book volumes and in the *Journal of Japanese Studies* and *Annals of Science*.

Miles studies the historical political economy of disability –broadly conceived– in the African diaspora and Vast Early America. His goal is to inform the public that the intertwined evils of racism and ableism were, and remain, foundational to modernity. He hopes that his research will help combat these twin prejudices in the sphere of public policy.

## 2020 DHA Journal Article / Book Chapter Awardees

Based on articles and book chapters published in 2019, this year's competition attracted an exciting range of quality writing. The adjudicators' evaluations resulted in recognition of two emerging scholars.

Coreen Anne McGuire of Durham University was declared the winner for "The Categorisation of Hearing Loss in Inter-War Telephony," *History and Technology* 35, no.2 (September 2019): 138-155.

Sam de Schutter of the University of Leiden was awarded the Honorable Mention with "A Global Approach to Local Problems? How to Write a Longer, Deeper, and

Wider History of the International Year of Disabled Persons in Kenya”, *Diplomatica* 1 (2019), 2: 221-242.

### Coreen Anne McGuire



The judges comments included: “A splendid piece, with great use of disability studies scholarship combined with the history of technology.” “... explores a largely neglected theme that places an interesting comparison of assumed state responsibility and deaf advocacy.” “... well-written, historically grounded, and provides a significant contribution to our understanding of how standards of normality and disability have been historically created outside of the medical sphere.”

Of her award winning entry, Coreen writes: “The article is a highlights version of my PhD thesis, which I completed at the University of Leeds in 2016. It analyses the specific kinds of bodies that have been used to create normalcy thresholds in order to reveal the social construction of disability through technology, such as telephony. As I elucidate in this article, assigning 'normal hearing' standards in the telephone system using an idealised average led to disconnect between the objective measurement of hearing and the subjective correlate. This connection fault meant that telephone users with hearing loss modified the technology to fit their personal needs, experiences and identities. This article therefore underscores two of the main insights driving my research: that technologies are crucial to our understanding of disability, and that disabled innovation is crucial to the development of technologies.”

Coreen is a lecturer at Durham University, before which she was based at the University of Bristol where she recently completed a Wellcome funded postdoctoral appointment on the Life of Breath project ([www.lifeofbreath.org](http://www.lifeofbreath.org)). Her book, *Measuring difference, numbering normal* is newly published by Manchester University Press: <https://manchesteruniversitypress.co.uk/9781526143174/>



## Sam de Schutter



Judges' comments on Sam's entry included: "This is a much-needed piece of work on disability in the global South, and it is clearly and cogently presented, making contributions to the history of disability and diplomacy alike." And, "Revealing on the disconnect between international goals and on the ground realities. Argues that what happened in Kenya had a lot to do with public health practices from the colonial era rather than adherence to international goals."

Sam writes: "In this article, I use the International Year of Disabled Persons (IYDP) in 1981 as an entry point to write a transnationally entangled history of disability in Kenya. The main argument is that the way in which this international event played out on the ground in Kenya can not be reduced to a story of 'global' approaches that clashed with more 'local' ways of dealing with disability. In order to move beyond those global-local dichotomies, I trace a longer, deeper and wider history of disability policies and interventions in Kenya, which draws inspiration from the historiography on development and especially the work of Joseph Hodge. In doing so, I point to the centrality of the concept of development in understanding how interventions, institutions and policies took shape, especially those centred around the concept of (vocational) rehabilitation. Writing a longer history shows how the approaches promoted during the IYDP can be traced back to at least late colonialism and the emergence of a 'developmental' colonialism; a deeper history shows how this event played out on the ground, rather than on an abstract global level; and a wider history lays bare the broad range of actors involved beyond 'the UN', such as national government officials, missionaries, and of course disabled Kenyans themselves."

Sam's personal twitter handle is @samdeschutter and he requested that we also acknowledge that his paper is part of his project, "Rethinking Disability" with the twitter handle @ERC\_Rethinking.

# Touch This Page!

## Sari Altschuler

In our Spring 2020 issue of DHA News we announced the winners of The Disability History Association's first biennial Public Disability History Award: Sari Altschuler and David Weimer with ***Touch This Page! Making Sense of the Ways We Read*** - <https://touchthispage.com>. Here, Sari Altschuler explains the winning project:

*Touch This Page! Making Sense of the Ways We Read* is a public disability history exhibition that invites visitors to develop a new understanding of their senses of reading through the history of tactile reading systems for people with blindness and low-vision. With a team of librarians, scholars, engineers, and staff from the Perkins School for the Blind we reproduced tactile facsimiles of pages originally printed for blind and low-vision readers in order to make the experience of reading these books publicly accessible for the first time in over a century. Through an exhibition organized around these objects, *Touch This Page!* enlivens issues of disability history through the widely shared experience of reading while illustrating how and why digital humanities projects must expand beyond principally visual forms.



*Touch This Page!* asks visitors to rethink how they read by defamiliarizing forms of reading. Developed in partnership with the Perkins School for the Blind, this experiential exhibition is structured around 3D-scanned and printed replicas of pages from books printed for Perkins's students in the nineteenth century. By experiencing these 3D-printed objects, visitors can reflect on how touch, sight, and sound contribute to reading. Simultaneously, they learn about disability history, and today's barriers to access, through principles of universal design and firsthand accounts of nineteenth-century blind readers.

Key to this project is our partnership with librarians and engineers at Northeastern University and librarians and archivists at the Perkins School for the Blind. With them, we have been able to realize an in-person and online exhibition on the history of reading and accessibility. At its foundation, our project brings the too little-known history of tactile text to a broad public through new 3D printing technology. Working with Perkins's archivists and blind and low-vision partners, we created a maximally accessible exhibition that asks visitors to reflect on how different printed forms make reading accessible for different bodies.

In 2019, we launched the project with a pop-up style version hosted simultaneously at eight locations in New York and Massachusetts (including Harvard, Northeastern, Perkins, NYU, Boston Public Library, Mount Holyoke, and Watertown Public Library) and online at [touchthispage.com](http://touchthispage.com). The website allows visitors to read or listen to the exhibition text, view and manipulate the central objects of the exhibition, and, most importantly, print their own 3-D pages.

The two chief innovations of *Touch This Page!* address how we can make disability history and its archives more accessible. First, by featuring artifacts that users can access anywhere, with widely available technology, through sight, touch, and/or hearing, the digital platform provides a new model of access to historical materials. In combining a multi-local exhibition with downloadable content, we offer an innovative twist on the public humanities concept of a traveling exhibition. Without physically travelling, *Touch This Page!* is available in a range of formats and locations from professionally built, publicly exhibited pieces to pages users can print at their local library makerspace or at home.

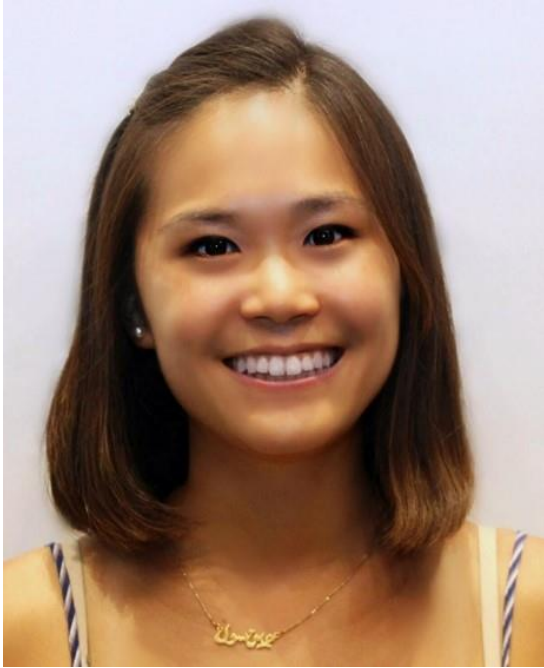
Second, *Touch This Page!* models a new kind of public Disability History project, challenging the visual bias of the digital humanities. Digital initiatives have made rare materials astonishingly more accessible; nevertheless, they have done so largely through the flat screen, inadvertently privileging sight as the key sense for acquiring knowledge. We show why touch must be a key element of public Disability History future projects, especially for projects seeking to make their content maximally accessible.

By linking disability history to common experiences and making it widely available through innovative, multisensory forms, *Touch This Page!* connects the public to vital histories that remain understudied because they are hard to access.

We are tremendously honored and grateful to the Disability History Association for awarding us the inaugural Public Disability History Award, which funds the website for the year 2020.

## **Jinseul Jun, DHA Intern**

*DHA's intern program provides practical skill and career development opportunities for students, while the interns provide a valued contribution to DHA's limited manpower resources. Here, recent DHA intern Jinseul Jun shares her first-hand experiences and her impressions.*



Disability rights have long been at the forefront of who I am.

I started this journey with seeing how my sister, who has a physical disability, has navigated systems in a very different way to me. I have had a particular interest in the promotion of disability rights in the Arab region and I became even more interested after reading Dr Sara Scalenghe's book *Disability in the Ottoman Arab world, 1500-1800* (New York: Cambridge University Press, 2014). Through my conversations with Dr Scalenghe prior to starting my MA program at Georgetown University, I was able to land on this exciting internship opportunity with the Disability History Association.

As a DHA intern, I mainly supported Dr Caroline Lieffers on transcribing recorded podcasts. I became heavily involved with the process, deciding when to transcribe verbatim, recognizing and appreciating pauses, and checking and double checking the transcriptions by listening to the podcasts three or four times to refine in order to refine them.

The podcasts included interviews with Jen Hale (archivist at the Perkins School for the Blind, MA), Jason Ellis (associate professor of educational studies at the University of British Columbia), and Bess Williamson (associate professor of art history, theory, and criticism at the School of the Art Institute of Chicago). Through this transcribing assignment, I was exposed to, and learned about, a wide range of topics including the history of special education and the intersection of disability design.

Having focused both my academic and professional work on disability policy/law, many of the podcast themes were new to me. Through this internship experience, I learned to appreciate the untold/unrecognized histories of disability and persons with disabilities.

## **Disability History Association - Outstanding Article / Book Chapter Award, 2021**

The Disability History Association (DHA) promotes the relevance of disability to broader historical enquiry and facilitates research, conference travel, and publication for scholars engaged in any field of disability history.

The Disability History Association takes pleasure in inviting entries for the Article / Book Chapter Award, part of its 10th Annual Outstanding Publication Award that also includes a separate Book Award.

In calling for article and edited collection book chapter submissions for the 2021 award, the award committee welcomes entries that feature new and original history of disability scholarship. To be considered, submissions **MUST** have significant historical content.

The award is open to authors writing across all geographic areas and time periods. The publication must be in English, and with first publication taking place between January 1 and December 31, 2020. We are conscious that some journals publish an electronic advance copy of articles that can appear a considerable time before the print copy is published; we also recognize that some journals are running behind schedule so that, for example, an article published in October 2020 might actually appear in a 2019 edition. First publication is the key criteria, but we will endeavor to be sympathetic in cases of “behind schedule” publication. If you feel that your proposed submission should be considered, but might be at risk of disqualification by definitions of “first publication,” please email for adjudication by the Awards Committee.

The amount of the award is \$200 for first place and \$100 for honorable mention.

All submissions should be sent to the award committee, via Iain Hutchison, no later than May 15, 2021. One electronic (.pdf or .doc) copy of the article or book chapter to be sent to: Dr Iain Hutchison, Centre for the History of Medicine, University of Glasgow; [iain.hutchison@glasgow.ac.uk](mailto:iain.hutchison@glasgow.ac.uk).

In the interest of modeling best practice in the field of disability history, we require that the publisher/author provide an electronic copy in text-based .pdf or .doc file compatible with screen reading software for the review committee. We understand that copyright rules apply, and we will only use the electronic copy for the purposes of the DHA Outstanding Publication Award. Manuscripts not provided in accessible electronic formats for screen reading software in a timely manner cannot be considered for the prize.

Please include the full bibliographic citation of your submission in the Chicago Manual of Style format.

The Disability History Association Board plans to announce the recipients of the DHA Outstanding Publication Award in September 2021.

Members of the DHA Board are not eligible for the award.

# Disability History Association - Outstanding Book Award, 2021

The Disability History Association (DHA) promotes the relevance of disability to broader historical enquiry and facilitates research, conference travel, and publication for scholars engaged in any field of disability history.

The Disability History Association takes pleasure in inviting entries for its Book Award, part of its 10th Annual Outstanding Publication Award.

In calling for book submissions for the 2021 award, the award committee welcomes monographs and edited collections, provided they are new original scholarship and published in English. The award is open to authors writing across all geographic areas and time periods.

The first publication of the book should have taken place between January 1 and December 31, 2020.

The amount of the award is \$300 for first place and \$100 for honorable mention.

Please send four copies of your book to the Chair of the Award Committee, Sara Scalenghe, Department of History, Loyola University Maryland, 4501 N Charles Street, Baltimore, MD 21210, USA. The deadline is May 15, 2021.

In the interest of modeling best practices in the field of disability studies, we ask that the publisher/author send an electronic copy in text-based .pdf or .doc file format compatible with screen reading software for the review committee to [sscalenghe@loyola.edu](mailto:sscalenghe@loyola.edu). We understand that copyright rules apply, and we will only use the electronic copy for the purposes of the DHA Outstanding Publication Award. Books not provided in accessible electronic formats for screen reading software in a timely manner will not be considered for the prize.

Please include the full bibliographic citation of your submission in the Chicago Manual of Style format.

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# Pandemics, Past and Present

Jessica Dimka

The COVID-19 pandemic has revealed, and worsened, health and socioeconomic disparities for people with disabilities and chronic health conditions. This group of people has higher rates of severe outcomes, including death, compared to the general population, while economic impacts are likely to have disproportionate effects on disabled people. These issues highlight the need for inclusive public health responses, which can be greatly informed by an improved understanding and awareness of the experiences of people with disabilities during past pandemics.

There are many reasons why disabled people are at increased risk from infectious disease epidemics. For at least some disabilities, the nature of the impairment or associated conditions might reduce a person's ability to fight off infection or lead to complications. At a broader level, social factors – access to health care, the ability to follow recommendations such as social distancing and hand washing, living conditions, exclusion from policy-making and decision-making and so on – also play important roles. These concerns are not unique to the COVID-19 pandemic, yet there has been limited work on these issues during past pandemics, at least from a social science or historical demography perspective.



My current research, as a Marie Skłodowska-Curie fellow, aims to fill in some of these gaps. I am studying disability as a risk factor during the 1918 influenza pandemic using Norwegian and Swedish records. Because of the long history of collecting demographic records in these countries, they contain rich and high-quality data. For example, in a paper recently published in the *Scandinavian Journal of Disability Research*, I combined information from annual reports of schools and

psychiatric hospitals with a published report on the pandemic experience in Bergen. [1] These sources allowed not only a general understanding of the introduction, spread of, and responses to illness within institutions, but also the type of quantitative analyses epidemiologists and policymakers tend to prefer.

These records showed that staff members were frequently the first cases, introducing the disease to the institutions often after traveling to neighboring communities. The flu typically would spread to other employees before affecting the disabled residents. Overall, far more of the staff members reported illness (53% vs. 24%), but residents were more likely to die (10% vs. 1%). The descriptions of the outbreaks were often brief, with little more than dates and numbers provided. However, occasional, less clinical phrases hinted at more in terms of both the experience itself and of potential attitudes to, or understanding of, disease and disability. For example, one school reported that the flu “ravaged badly”, while a psychiatric hospital noted that all deaths occurred among the “dullest and physically most frail” patients.

These results are particularly relevant given the high risks and rates of severe outcomes for COVID-19 seen in nursing homes and other institutions. Rapid and deadly spread of infectious diseases in such living situations are neither surprising, nor unusual, reinforcing the need for deinstitutionalization and the development of better protocols and solutions. However, now and in the past, institutionalized populations represent only a fraction of disabled people. Public health surveillance, censuses, and other records do not always collect information on disability among the general population even today, and it is even more difficult to find reliable historical data.

However, Swedish records provide an opportunity to investigate the experiences of non-institutionalized disabled people during the 1918 flu. Parish registration was legally regulated from at least the late 1600s, and clergy maintained detailed records of residents in their parishes, including not only births, marriages and deaths but also information about, for example, literacy, vaccination and disabilities. Drawing on the Demographic Data Base at the Centre for Demographic and Ageing Research at Umeå University, I am currently exploring the records of over 22,000 people living in nine parishes between 1918 and 1920. Based on a system developed by Lotta Vikström, Glenn Sandström and colleagues to classify the various remarks into broad disability types (e.g. blindness, psychological, mobility), approximately 3% of the sample had a recorded disability. Preliminary analyses suggest that fatality rates among disabled people were significantly higher than for those without a recorded disability.

While history does not exactly repeat itself, research on historical pandemics allows for nuanced exploration of rich contextual data, dynamic and interacting factors, and short- and long-term outcomes. Historians therefore can play an important role in contributing to the evidence base used in public health practice, developing equitable policies, and uncovering the experiences of individuals in the past to add further depth to current events. Particularly from a disability perspective, knowledge about how people defined and counted disability in the past, how those understandings



varied in different contexts, and how they were used to determine treatment in both everyday life and during medical crises like pandemics can help raise awareness and inform responses now and in the future. As the COVID-19 pandemic reminds us, we do not just study history – we also live through it and help shape it.

1. <https://www.sjdr.se/articles/10.16993/sjdr.725/>

## **Treading familiar paths: COVID-19 and Intellectual Disability in Ireland**

David Kilgannon

My aunt rubbed her hands together. It's a tick she's had since childhood, a clear sign that she was nervous. The staff in her group home for intellectually disabled adults did their best to distract her, talking about the activities and hobbies that she would do following her COVID-19 test that afternoon. 'I'm still not allowed to go out though', she explained to me later, 'because we're all supposed to be locked up here'.

COVID-19 poses an unprecedented range of challenges to Irish society. It is more telling to see what has not changed in the face of this global pandemic. While thousands have documented their struggles with confinement in their homes, isolation wasn't a new trend for the state's intellectually disabled. Despite significant advancement over the past sixty years, those with ID continue to face notably high levels of social marginalisation, housing challenges, and segregated education. COVID-19 did not create these long established issues. It has, however, thrown into relief the strengths and deficiencies inherent to the Irish approach towards the intellectually disabled.

The marginalisation of the disabled was particularly apparent in the limited discussion of the viruses' impact on community-based group homes. These accommodation programmes, based on a 'normal' estate, have provided housing for small groups of the intellectually disabled since the late-1970s. They have also proven to be a clear vector for this virus. A study of similar facilities in New York City found that residents were five times as likely to contract the virus versus the general population. There have been similar issues in Ireland, where more than one hundred cases of COVID-19 have occurred in disability-specific accommodation.



To an extent, this can be explained given the challenges associated with taking necessary precautions inside these facilities. Staff members have struggled to discuss ideas like hand hygiene and social distancing with some of their residents. They're not alone. A study by the American Academy of Developmental Medicine found that over 80% of medical students had no training in how to deal with the intellectually disabled or how to discuss medical ideas with this constituency. This does not bode well for the training available to the care staff working in these centres, who spend most of their day with these residents and who were responsible for ensuring their health and welfare throughout this period of crisis.

Problems for staff members have been compounded by the structure of the disability sector in Ireland. During the economically challenging early decades of the state, the Department of Health focused on developing services in collaboration with religious orders, which lead to the propagation of a range of religious-operated hospitals, industrial schools and 'mother and baby' homes. In the disability sector this trend was reflected in the dominance of Catholic religious orders, who owned and operated the majority of residential institutions throughout the twentieth century.

This structure, which was sometimes justified in terms of the Catholic religious doctrine of *subsidiarity*, placed disability services at a distance from the state. These facilities remained a charitable privilege that received state funds, rather than a state service that was operated through the voluntary sector. The continuation of this established practice has meant that the majority of 'mental handicap' services have remained in the voluntary sector into the twenty-first century, with more than 300 individual charities operating a variety of facilities for the intellectually disabled.

This approach has facilitated flexibility and a diversity of supports for the disabled, but it equally means that services can vary across the country with little standardisation in their approach. In practice this meant that, while one centre could become a site for multiple COVID-19 infections, others could prove more adept in their response to the disease. The charitable orientation of services has also compounded challenges for some facilities, as they worked to procure PPE and expand their infection control protocols.

This is not to deny their many strengths. The standard of care in these centres remains exemplary, while multiple families cite these services as an essential component in supporting the intellectually disabled adult to live outside of the family home. Yet, the COVID-19 pandemic has shown how the charitable ethos can isolate some facilities, leading to challenges and approaches that can risk an outbreak. The past twenty years have seen steps to integrate disability services under the umbrella of the national charity Inclusion Ireland, leading to greater dialogue and standardisation of services across the country. Yet, there is clearly more work to do to ensure that community accommodation remains resilient to face these new challenges.

Thankfully, my Aunt's COVID-19 test came back negative, and she eagerly returned to her daily exercise outside. Yet, she was a lucky resident within a system that remains clearly shaped by long established practices. COVID-19 has made clear the challenges (and opportunities) associated with this approach.

## History Repeating ... Disability in the Time of COVID 19

By Nancy E Hansen

March 13, 2020. This is going to be bad I thought to myself. How long will it take? I did not have long to wait for the answer. A few weeks after the World Health Organization (WHO) Pandemic Declaration, media articles began to appear world-wide. They were openly speculating that medical treatment should be withheld from disabled people in order to conserve scarce medical resources (McCloskey, 2020). Furthermore, systems of triage were uncovered specifically downgrading the treatment priority of disabled people (Solomon et al. 2020). As a disabled person, this is not a theoretical discussion. My life, quite literally, depends on it:

*“People with Down syndrome could be left to die of coronavirus to ‘save’ medical supplies”* (McCloskey, 2020)

*“Americans With Disabilities Are Terrified They fear they could be denied life saving treatment if they end up in the hospital with COVID-19”* (Godfrey, 2020)

Strange how medical resource limitations had not been pointed out previous to this. Being declared surplus to requirements is extremely disconcerting to say the least. However, writing for one's life underscores just how tentative social positioning really is. Understanding this 'new' reality enables personal clarity, conciseness and serious reflection. In times of perceived threat, the goal posts can change abruptly. Society can shift from us to them and other overnight. The new borders are rarely determined by those most directly affected (Wolbring, 2003). Qualities previously framed as distinctive and unique are suddenly viewed with suspicion.



Throughout history, disabled people have repeatedly been placed in this position. Determinations of capacity are often highly subjective, based on so-called abhorrent physicality and outdated understandings of disability and misconceptions of the body as machine disability being defined as burdensome and useless. (El-Lahib, 2016).

Early in the 1930s, the Nazi regime's T4 extermination program was developed as a precursor to the Holocaust. Thousands of disabled people were killed -- before many other marginalized population groups (Evans, 2004).

Eight decades on from the extreme proponents of the Nazi eugenics program and the Final Solution, how far have we come? Discussions are lead, programs and policies developed by individuals who remain distant from the real quality of life and actual lived experience of disabled people (Capurri, 2020). Discussions of disability and disability issues often remain fraught with social and cultural discomfort.

“Despite the significant advances in the recognition of the rights of persons with disabilities at international and national levels, the deeply rooted negative perceptions about the value of their lives continue to be a prevalent obstacle in all societies. Those perceptions are ingrained in ableism—a value system that considers certain typical characteristics of body and mind as essential for living a life

of value. Based on strict standards of appearance, function and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage, and invariably devalues human life. As a result, it is generally assumed that the quality of life of persons with disabilities is very low, that they have no future to look forward to and that they will never live happy and fulfilling lives” (UN Special Rapporteur, 2019, p.3).

“Proponents of eugenics believe that disability and illness are largely the fault of the disabled and the sick and that society is made better by weeding out weakness ... Public health policy, in the face of a disease like this, requires not only compassion but also an understanding that disease doesn’t just affect the weak or the already disabled. Yet, again and again, Trump and his administration have promoted the idea that Covid-19 is only dangerous for those who are already vulnerable.” (Perry, 2020). Such ‘reasoning’ provides the necessary reassurance to the majority maintaining the comfort of social distance between ‘us and them’. COVID 19 had the greatest impact on the elderly, vulnerable and the disabled. Reducing people to a series of singular identifiers and abstract utility seems to betray an underlying primitive attitude of disposability of those individuals deemed to be less worthy. “There is often a tendency to conflate quality of life with worthiness to live.” (Hansen and Janz, 2009, p. 30) Society can often lack imagination when it comes to bodies of difference (however that is framed), working in a unique way. Disability is regularly associated with incapacity, weakness and pain. Fear and ignorance do not work to promote awareness, understanding or effective policy development.

Disabled people have paid a heavy price throughout this Pandemic. In the UK alone, it has been estimated that as many as two-thirds of COVID-19 related deaths are people with disabilities (Webster, 2020). According to the United Nations, similar numbers have been replicated world-wide.(UN, 2020). COVID 19. has uncovered long-standing gaps and weaknesses in program and service delivery for disabled people. At the same time, the Pandemic has served as the vehicle to justify service reduction or elimination. Services and programs for disabled people are rarely defined as essential and, consequently, social isolation was even more extreme (Martino, A, 2020). However, the Pandemic is not without some positive changes for disabled people. For decades now, disabled people have advocated for the opportunity to work remotely. However, the option had not gained wide acceptance prior to the onset of COVID 19.

“Disabled employees have benefited from remote working for a variety of reasons - travel is often disproportionately difficult for disabled people, and office environments themselves can be disabling. People with visual impairments who rely on screen readers may be unable to access information properly with the noise of a typical open-plan office, while neurodiverse employees may struggle to focus in an environment they have little control over.” Jane Hatton, the founder of EvenBreak, (where every member of staff has a disability or health condition) explains, “We all work remotely, from home ... [which] means we can offer a totally flexible working environment. For example, if someone has a condition such as ME, which means they need to work in short bursts and then rest, working from home makes that totally doable.” (Policy Connect April 1, 2020)

COVID 19 has illuminated the troubling reality that is systemic ableism as yet largely unacknowledged and misunderstood. There are difficult questions that need to be dealt with and uncomfortable conversations to be had. Why are disabled people so

readily discounted and 'disappeared'? At present, toleration would appear to be the goal. It is a far cry from acceptance and certainly not inclusion. Hopefully, this will begin the conversation.

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## DHA in August

DHA Board Members had a combined presence on two occasions in August.

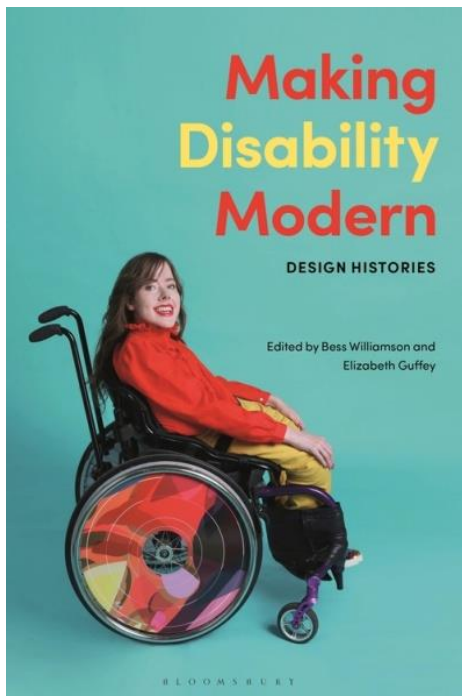
There was the publication by Bloomsbury of Bess Williamson's and Elizabeth Guffey's edited collection, *Making Disability Modern: Design Histories*. Among the thirteen chapters, four DHA board member contributions are to be found:

Of Ear Trumpets, Audiphones and the 'Language of the Fingers' (Kar Pallavi Bhasha): Technologies for the Deaf in British India, 1850-1950, *Aparna Nair*

Imperial Designs: Artificial Limbs on the Panama Canal, *Caroline Lieffers*

Materializing User Identities and Digital Humanities, *Jaipreet Virdi*

The Material Culture of Gout in Early America, *Nicole Belolan*



The book comes in several formats. See: <https://www.bloomsbury.com/us/making-disability-modern-9781350070455/>

The online **Hidden in Heritage Festival** was organised by *Hidden Disabilities Sunflower*. The one-day Festival included presentations by Aparna Nair, Jaipreet Virdi with Coreen McGuire, winner of this year's DHA journal article prize, and Iain Hutchison.



The paper titles, with YouTube links, are:

Aparna – ‘Epilepsy Histories: Hidden and Concealed’.  
<https://www.youtube.com/watch?v=l4O-Uj2aT1Y&feature=youtu.be> (Aparna’s presentation begins at 18:58)

Jaipreet and Coreen – ‘Objects fo Concealment and Power’.  
<https://www.youtube.com/watch?v=ZV-SLzG9-po&feature=youtu.be>

Iain – ‘The Hidden Histories of people with sight loss in Edwardian Edinburgh and the Scottish Borders’. <https://www.youtube.com/watch?v=g1tAdZz7ye0>





## DHA Membership

Membership dues support the organization's activities and goal of promoting the study of the history of disability.

A one-year (January 1 to December 31) individual membership in the Disability History Association is thirty (\$30 U.S.) dollars. We offer a student/low or fixed income membership of fifteen (\$15 U.S.) dollars per year. The DHA also offers institutional memberships at the rate of one hundred (\$100 U.S.) dollars per year (see below), and lifetime memberships for five hundred (\$500) dollars. If you are a U.S. citizen, your dues are tax deductible.

To join the Disability History Association, please fill out the form under Membership on the website. Dues may be paid through PayPal.com, or you may send a check or money order (made payable to the Disability History Association) to the address below. When you submit the form you will be transferred to <http://www.paypal.com> where you can pay online. If you would prefer, you can simply submit your information and send a check or money order to our Treasurer, Kathleen Brian:

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We respect your privacy and will keep the information you provide confidential.

For questions about membership and dues, please contact Kathleen Brian, DHA Treasurer, at [disability.history@gmail.com](mailto:disability.history@gmail.com).

## DHA News

We hope that you have enjoyed reading this newsletter. How about writing for the next one? Short articles or story pieces. New research projects. Letters to the Editor. Finds in the Archive, such as unusual pieces of disability history that you have discovered in unusual places. Photos and other visual material – with the usual permissions and credits where applicable.

Or just drop an email to say 'Hi!' – to Iain: [iain.hutchison@glasgow.ac.uk](mailto:iain.hutchison@glasgow.ac.uk)