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Proximity Matters:

Disability, Erasure & the Archival Bond of Natural History

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Philosophy

in Information Studies

by

Gracen Mikus Brilmyer

2020

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2020

ABSTRACT OF THE DISSERTATION

Proximity Matters:

Disability, Erasure & the Archival Bond of Natural History

by

Gracen Mikus Brilmyer

Doctor of Philosophy in Information Studies

University of California, Los Angeles, 2020

Professor Michelle L. Caswell, Chair

This critical archival studies dissertation examines the subtleties of disability in records by broadly asking "how can we tell a history of disability with little to no forms of archival evidence?" I attempt to answer this question by interrogating the contents of historical documentation, the archival processes that influence their understanding as well as disabled people's experiences in archives today. This project begins with the disabled community: through interviews with disabled scholars, artists, activists and community members, it first draws out the effects and affects of archival representation and archival spaces on the disabled community today. Then, in response to the disabled community's need for more complex representation, it closely examines a history where disability has been obscured or erased: The

Field Museum of Natural History in Chicago. To do this, historical records, processes, and documentation are closely analyzed in order to excavate narratives of disability within the history of The Field Museum and demonstrate how a history of disability can be told even through its absence. This dissertation develops the theoretical scaffolding of a *crip provenance*: a disability-centered framework that resists the desire to restore a 'complete' fonds and instead meets records where they are at in order to acknowledge all of the new connections and relations that are created because records are always already dispersed, duplicated, and partial. Drawing attention to how many archivists work to reconcile with records that have been moved, rearranged, and dispersed, to reconstruct a fonds, this framework highlights the 'curative' and 'rehabilitative' orientations of provenance—the emphasis of the origin, history and custody of a record or fonds. Put in conversation with disability studies scholarship—which critiques rehabilitating, curing, and restoring—the concept of provenance can be radically refigured, placing less emphasis on 'fixing' or reconstructing a fonds (which might have never been in the first place), and instead addressing the reality of archival material to acknowledge the new relationships created because they are always already fragmented. Acknowledging archival realties with specific attention to the people, systems, materials, and spaces that are in relation to disability and archives, a crip provenance places focus on the new relationships and proximities that are established because they are always already dispersed, duplicated, and incomplete, which can facilitate in an expansive re-reading of archival absences, partialities, and experiences of disability.

The dissertation of Gracen Mikus Brilmyer is approved.

Anne J. Gilliland

Ellen Pearlstein

Alison Kafer

Michelle Caswell, Committee Chair

University of California, Los Angeles

2020

This dissertation is dedicated to Disabled people, past, present, and future.

Table of Contents

Introduction: Disability, Natural History & Records 1
Introduction 1
Chapter Layout 9
References 18

Chapter One: Theoretical Framework | Towards a Crip Provenance 20
Introduction 20
Records' Reality 25
Archival Context & Provenance 29
Critiquing Provenance & the Desire for a Whole 36
Reorienting Towards a Crip Provenance 44
References 59

Chapter Two: Research Design | Methodology & Methods 66
Introduction 66
Methodology 66
Methods for Data Collection 74
Semi-Structured Interviews 76
Study Design 81
Participant selection 83
Confidentiality & Consent 84
Historical methods 85
Selection of Sites 89
Selection of Materials 92
Data Analysis 95
Limitations of the Study 100
References 102

Chapter Three: People | "It felt like everything": A perverse absent-presence and the creation of archival interdependence 111
Introduction 111
Disability Representation in Archives & Archival Affect 113
Disability & the Value of Community 118
Findings 122
Finding 1: Violence in Misrepresentation 123
Finding 2: Expected Erasure 128
Finding 3: Criticality of Misrepresentations & Erasure 133
Finding 4: Affective Impacts & Political Potential 138
Discussion 144
Conclusion 150
References 153

Chapter Four: Systems | Archival assemblages: applying disability studies' political/relational model to archival description 156
Introduction 156
Why Feminist Disability Studies for Archival Description? 159
Models of Disability: Medical, Social, Political/Relational 164
A Political/Relational Model for Archival Description 169
Illuminating Archival Assemblages 176

Conclusion . . . 191
References . . . 199

Chapter Five: Materials | Chemical Assemblages: Locating Disability in History & the Materiality of Labor . . . 209
Introduction . . . 209
Chemical Histories & Institutional Foundations . . . 215
Expanding Chemical Assemblages: Materiality of Labor & Toxic Exposure . . . 221
Conclusion . . . 240
References . . . 246

Chapter Six: Spaces | "it wasn't necessarily designed with that experience in mind": The Affect of Archival (In)Accessibility & "Emotionally Expensive" Spatial (Un)Belonging . . . 260
Introduction . . . 260
Accessibility, Legislation & Design . . . 264
Accessibility & Libraries, Archives & Museums . . . 270
Accessibility & Affect . . . 274
Findings . . . 277
Finding 1: Awareness of the Privileges of Access . . . 277
Finding 2 (Some) Logistics of Archival (In)Accessibility . . . 281
Finding 2.1 Spatial Access . . . 281
Finding 2.2 Digital Access . . . 285
Finding 3 The Affects of (In)Accessibility . . . 289
Finding 3.1 Material Affects . . . 289
Finding 3.2 Affects of Archival Use & Personal Belonging. . . . 295
Discussion . . . 298
Conclusion . . . 307
References . . . 311

Conclusion | Disability & Its Absence . . . 319
Towards a Crip Provenance. . . . 320
Archival and Disability Methodologies . . . 324
Absences of Disability & the Archival Grain . . . 329
Disabled Archival Users . . . 334
Future Research . . . 337
References . . . 339

Appendices . . . 343
Appendix A: Interview Questions . . . 343
Appendix B: Consent Form . . . 344

Table of Figures

Figure 1: Archival and disability relationships that form the four facets of a crip provenance... 58

Acknowledgements

I would like to thank the many individuals and organizations that made this research possible. First, thank you to my dissertation committee, Michelle Caswell, Anne J. Gilliland, Ellen Pearlstein, and Alison Kafer. To my advisor, Michelle Caswell, I have so much gratitude for your radical support and mentorship, critical and prompt feedback, and the ways in which you've taught me research, scholarship, and academic accountability. To Anne J. Gilliland, for your wisdom on archives and human rights, our conversations around historically contextualizing research, as well as your support and the ways in which you've created more accessible academic environments. To Ellen Pearlstein, whose kindness, generosity, and critical feedback around museums, conservation, and communication in this research was central, especially around the intersection of archives and museums. And to Alison Kafer for your attention to the balance of nuance and translation, specificity and generalizability and the politics of disability and language, as well as for your scholarship and for holding space for me as a Disabled academic.

A huge thank you to all of my participants, without which this research would not be possible. Your generosity in sharing your experiences, space, and emotions has provided this research such a profound foundation and has shaped the ways I think about records on disability. I am honored to be in community with you, to elevate your words, and to generate knowledge alongside you.

I also want to thank my disabled communities broadly—in Chicago, the Bay Area, Los Angeles and online—I am forever grateful for your generosity, ideas, art, support, and activism that continue to shape who I am and how I conduct scholarship to be accountable to you.

This research would not have been possible without the generosity of the many archivists and archives workers who not only facilitated my research but also went above and beyond to discuss with me the nuances of collections, allowed me access to records' provenance files, and shared insights to their labor with me. Thank you to Armand Esai, Gretchen Rings, Lesley Martin, Gretchen Neidhardt, Johanna Russ, Morag Walsh, John Cahoon, and the many other archivists, reading room staff, interns, and volunteers whose labor supported this research.

I also want to acknowledge my Field Museum colleagues, many of whom work towards racial, gender, disability, and environmental equity and justice, who are grappling with the history of our profession(s) while also fighting for a better future.

Thank you to my many collaborators, friends, and comrades with whom I have built an intellectual, emotional, and justice-oriented community. My deepest gratitude to my LA-based comrades: María Montenegro, Carlin Soos, Joyce Gabiola, Ayantu Tibeso, Yvonne Eadon, Ruth Livier, Lauren Sorensen, and Ulysses Pascal, with whom I've grown alongside and because of. To my UCLA friends and colleagues for creating an intellectual home, specifically Rachel Lee, Alexandra Apolloni, and Kristina Magpayo Nyden at the Center for the Study of Women, Pia Palomo and Juliann Anesi at UCLA's Disability Studies minor and reading group, and the many people who supported my research, collaborated on accessibility actions, and participated in expansive conversations around disability. And to my Archives PhD community, specifically Itza Carbajal, Ted Lee, Jessica Lapp, Brian M. Watson, aems emswiler, and Sam Winn, as our writing group and conversations have sustained me, my writing, and this dissertation.

Thank you to my family, biological and chosen, for your love, inquisitive conversations, and unwavering support in my work, academic and otherwise.

Vita

Gracen Mikus Brilmyer

Education

2016 Master of Information and Management Systems, University of California Berkeley

2008 Bachelors in Fine Arts, School of the Art Institute of Chicago

Selected Publications

Brilmyer, Gracen M. "'It Could Have Been Us in a Different Moment. It Still Is Us in Many Ways': Community Identification and the Violence of Archival Representation of Disability." In Sustainable Digital Communities, edited by Anneli Sundqvist, Gerd Berget, Jan Nolin, and Kjell Ivar Skjerdingstad, 480–86. Lecture Notes in Computer Science. Cham: Springer International Publishing, 2020. https://doi.org/10.1007/978-3-030-43687-2_38.

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Selected Awards & Fellowships

2020 Hugh A. Taylor Prize, Archivaria
2019 Andrew Horn Memorial Fellowship, GSE&IS, UCLA
2019 Penny Kanner Dissertation Research Fellowship, Center for the Study of Women, UCLA
2019 Best Student Paper Award, Archival Education and Research Initiative (AERI)
2019 UCLA Information Studies Dissertation Proposal Award, GSE&IS, UCLA
2018 Library Juice Press Annual Paper Contest, Litwin Books, LLC
2018 Graduate Summer Research Mentorship (GSRM) Award, UCLA Graduate Division
2017 Center for the Study of Women Travel Grant, UCLA
2017 Graduate Summer Research Mentorship (GSRM) Award, UCLA Graduate Division

Introduction
Disability, Natural History & Records

Introduction

I long to tell a story that's often impossible to tell—a story about disabled people in history outside of traditional forms of documentation, a story not just about the oppression, criminalization, and spectacularization of disabled people but also about our knowledges, resilience, complexities, and politics. Broadly speaking, this critical archival studies dissertation addresses the question, "how can we tell a history of disability with little to no forms of archival evidence?" I started my attempt to answer this question by looking at records from the Field Museum of Natural History Archives in Chicago—but wound up elsewhere—looking at records that document the Field Museum that are located at a plethora of institutions as well as interviewing disabled people across the U.S. and Canada who have used archives. I chose the case study of the Field Museum based only off of rumors from my disabled community that there were *possibly* disabled people who were involved in the history of the museum; but as of yet, nothing has surfaced confirming such rumors. Through this case study I began investigating archival representations of disability—the visual and textual contents of records—as well as the ways that records are processed, organized, and described in archives. This dissertation began with research around the Field Museum, looking for ways to tell a history of disability, but also inspired a second research method of interviews with disabled people as I reflected on my experiences in archives as a disabled person.

The Field Museum was founded out of Chicago's 1893 World's Columbian Exposition (WCE), also known as the Chicago World's Fair.[1] Marking 400 years after Christopher Columbus' voyages to the New World, the 1893 World's Fair is often cited as influential in the development of pedagogies of display as well as biological and anthropological discourses around difference, demonstrating white, Western, colonial dominance over other cultures and species. The fair brought millions of visitors to witness cultural, technological, and biological wonders from across the world. Not only would guests be mesmerized by bizarre animals, such as the wooly mammoth, and contemporary architectural feats such as the ferris wheel, but they could also experience "native villages", exotic cultures and bodies on display.[2] Given the central display of human difference, the fair attracted many showmen, such as John T. Ringling, founder of The Ringling Brothers, and Samuel W. Gumpertz—regarded as the most important freak show promoter of the nineteenth century and known as the 'godfather of the Coney Island Freak Show[3]—who took note of the ways in which people were spectacularized and exhibited, and many would later come to gain notoriety for their own spectacularized displays of difference,

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[1] Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit* (University of Chicago Press, 1990), 48.

[2] The Official Guide to the World's Columbian Exposition boasts, about the central fairgrounds, the Midway Plaisance, which hosted a number of 'living museums': "There are canoes in plenty, and at various points through the lagoons the curious visitor may occasionally see a stray Indian, in aboriginal costume, paddling among the electric launches and gondolas." What is more, guests could get a first hand look at a "living example of the principal families of native American Indians, who have made their temporary home on the Fairgrounds, living in the exact way their forefathers lived before the white man invaded their hunting grounds." Seven members of the Kwakwaka'wakw from British Columbia, additionally, lived in a reconstructed village at the fair, where visitors could witness "savage" cultural practices. The native villages were not limited to the US and Canada. Guests could look at "savage" cultures on display in villages or reconstructed scenes from around the world.
Official Guide to the World's Columbian Exposition in the City of Chicago ...: May 1 to October 26, 1893 (Columbian guide Company, 1893), 40; Paige Raibmon, "Theatres of Contact: The Kwakwaka'wakw Meet Colonialism In British Columbia and at the Chicago World's Fair," *Canadian Historical Review* 81, no. 2 (June 1, 2000): 157–90, doi:10.3138/CHR.81.2.1, 57.
Rossiter Johnson, *A History of the World's Columbian Exposition Held in Chicago in 1893;* (New York, 1897), http://hdl.handle.net/2027/mdp.39015009238216, 483.

[3] Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit* (University of Chicago Press, 1990), 57.

often featuring disabled people. Therefore, the WCE is cited as foundational and heavily influential to freak shows, sideshows, and other exhibition pedagogies of difference and deviant *bodyminds*—a term Sami Schalk describes as "the intertwinement of the mental and the physical—in the context of race, gender, and (dis)ability."[4] Not only did the Chicago World's Fair inspire many showmen who later came to found their own freak shows, but the display of disability was also central to subsequent World's Fairs. James W. Trent, looking at the 1904 Louisiana Purchase Exposition in Saint Louis analyzes how discourses around disability—"the blind and the deaf, the feebleminded, and premature babies"—developed in World's Fairs as a primary method of the exploration and categorization of difference and 'societal problems'.[5]

Although, as this literature shows, disabled people were impacted by the Chicago World's Fair—through the subsequent establishment of freak shows, the ways in which showmen were influenced by other methods of display, as well as the featuring of disabled people in future fairs—it remains unclear if people were displayed because of (perceived) disabilities at this specific fair or in the history of the Field Museum. I heard rumors of disabled people being on display at the WCE through an initial conversation with disability studies scholar, Sue Schweik, which I then discussed with disabled activist and author Corbett OToole. Both pointed me to resources and people knowledgeable on World's Fairs and the history of the display of disabled people. Yet, as I combed through others' research, I still did not find any concrete evidence of disabled people at the WCE. This absence only grew my curiosity around how to approach a history that may be impossible to tell and led me to turn to the archival

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[4] Sami Schalk, *Bodyminds Reimagined: (Dis)Ability, Race, and Gender in Black Women's Speculative Fiction* (Durham: Duke University Press Books, 2018).

[5] James W. Trent, "Defectives at the World's Fair: Constructing Disability in 1904," *Remedial and Special Education* 19, no. 4 (July 1, 1998): 201–11, https://doi.org/10.1177/074193259801900403, 201.

material that documented the event to look for traces of disabled people while also being constantly confronted with their absence.

Frequently, disabled minds and bodies have historically entered into archives and records through the criminalization, spectacularization, and medicalization of disabled—and other marginalized—identities, frequently resulting in the creation of legal, medical, and institutional records making up a plethora of records documenting disability. Due to public treatment of disability as well as societal norms that framed disabled people as pitiable or frightening, to be institutionalized or 'cured', *records* such as institutional, medical, or freak show documentation are arguably some of the most dominant forms (or most easily found) documentation of disability. Some disabled people have historically been policed for being disabled, poor, or 'unsightly' in public, whereby they were arrested, marked as dangerous, and often institutionalized,[6] whereas others were documented as they entered into rehabilitation centers, freak shows, asylums, and medical facilities. Kim Nielsen writes about the contradictory ways in which disabled people were documented during the nineteenth century. While anti-begging laws (also known as ugly laws) flourished—and through such laws disabled people were often policed and arrested for being in public—"at the same time, the public seemed to have an expanding and insatiable curiosity about deviant bodies."[7] Nielsen describes how such curiosities influenced not only the development of fields of medicine that studied non-normative bodies, but also the growth of industries such as freak shows, "circus side shows and World's Fairs, [and] the exhibition of human bodies considered both wondrous and freakish drew huge crowds always

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[6] Jacobus tenBroek, "The Right to Live in the World: The Disabled in the Law of Torts," *California Law Review* 54, no. 2 (May 31, 1966): 841, https://doi.org/10.15779/Z384J44; Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010).

[7] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 89.

willing to hand over their cash."[8] Along these lines, disability studies scholar Rosemarie Garland-Thomson traces the public spectacles made through Julia Pastrana's life and death as she was advertised as a bearded Lady or "The Misnomered Bear Woman" and "was managed by a man who married her after she became extremely profitable, perhaps to assure his control over her exhibition."[9] After her death during childbirth, her husband/manager sold Pastrana and her son's bodies for embalmment, scientific study, and display, only to buy them back to tour and display himself. Records—such as her marriage certificate that ensured her husband's profit, medical journals that documented and debated her physical differences, and the advertisements for her shows that produced a profit—demonstrate the power others had over her life and the power that different types of records had in documenting her. These examples show how the criminalization, medicalization, and spectacularization of disabled people resulted in certain types of records on disability: arrest records, medical and asylum documentation, as well as freak show advertisements and photographs.

While medical, institutional, criminal, and freak show records are each produced through different systems, by different people, and represent disabled people in different ways, by providing this overview, I aim to illustrate the entanglement of such records: as legislation, medical records, newspaper articles, and other documentation reflect cultural and societal values, they also can reinforce stigma and influence the production of other records. This is not to say that disabled people only entered into records in these ways or that they had no agency in their display, their documentation, and their lives, but that I'm interested in what these types of documentation do—while a disabled person could have agency in their display, or consent to

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[8] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 89-90.

[9] Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, 1st edition (New York: Columbia University Press, 1996), 76-77.

being photographed, the ways in which documentation functions sometimes reinforces social stigmas as well as how others come to understand disability. And in thinking through the history of documentation of disability, I am confronted with these dominant forms, each of which is embedded in their own histories—histories of science, medicine, capitalism, and colonialism that are geographically and temporally contingent—that sometimes overlap.

Due to the prominence of these types of archival representations, disability history is frequently considered separate from other histories, relegated to medical history, carnival documentation, canonical moments of the disability rights movement, and other often stereotypical representations of disability-centered events. And the way disability has been historicized, in turn, informs how disabled bodyminds are understood and treated today: despite the rise of disability justice and activism, disability continues to be predominantly conceptualized in medical terms, which perpetuates stereotypical understandings of disabled people. I write this dissertation in a moment in the United States where disabled people are continually advocating for their right to access health care, fighting to gain social support, and are frequently understood as apolitical, ahistorical, lesser than 'normative' bodyminds, and thus in need of 'fixing'.[10] Considering the abundance of such types of records that tell *one side* of disability history and knowing how disabled people have existed throughout history but aren't often documented unless we're being surveilled, I want to look elsewhere—and sometimes fail—to locate histories where we might not be apparent, obvious, or necessarily documented at all. Moreso, in the prevalent absence of disability, I also center ableism as a way of tracing our

[10] I'm also finishing this dissertation in the time of COVID-19, where disabled people are feeling the threat of being denied treatment due to pre existing conditions, seen as the 'collateral damage' of a pandemic where only the "strong" survive, and are also fighting for justice on behalf of the disproportionate number of Black disabled people killed by police.

histories: how underlying values of bodies and minds inform institutions and their systems of documentation, preservation, and access.

In attempts to retell histories and redress them with disability at the center, I turned to the archival materials that document the Chicago World's Fair and the history of the Field Museum, while also broadly thinking about 'records' as any evidence of an activity.[11] But tracing this history was no easy feat. Located at several different archives, the materials that document these histories were created by multiple people—tourists, exhibitors, museum curators, etc.—governing bodies, and entities. As I will discuss in detail in the next chapter, the materials are not only dispersed across different sites—all of which have varying levels of accessibility—but are also duplicated, organized according to different schemas, and described in different ways, with varying amounts of detail in finding aids. In other words, the documentation of these events are not a single (or even a few), 'clean' archive(s). Through an attention to the contents of such records and also the decisions made within archives—as Anne J. Gilliland identifies, archives are not neutral arbiters of materials and can have social justice impacts on how we contextualize history[12]—I examine the messiness of archival realities to consider multiple ways of addressing history. Furthermore, as I combed through archival material and thought about the relationships among records, I could not ignore my own experiences as a Disabled person in archival spaces: my affective experience of looking for disability, finding violent or problematic records, or not being able to find anything at all. This drew me to develop a complimentary research method: to interview disabled people about their relationships to archives as to not only focus on the

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[11] Geoffrey Yeo, "Concepts of Record (1): Evidence, Information, and Persistent Representations," The American Archivist 70, no. 2 (2007): 315–43.

[12] Anne Gilliland, "Neutrality, Social Justice and the Obligations of Archival Education and Educators in the Twenty-First Century," *Archival Science* 11, no. 3–4 (November 1, 2011): 193–209, https://doi.org/10.1007/s10502-011-9147-0.

perspectives provided from archives and archival material, but also root this research in the context of how living disabled people are impacted by archives today. The absence of much documentation around disability led to me to draw on theories from both disability studies and critical archival studies in order to develop a framework for telling a history of disability when it may not be obvious.

Lying at the intersection of disability studies and archival studies, this critical archival studies dissertation turns attention towards the relationships that are created both through archives and disability. Critical archival studies, Michelle Caswell, Ricardo Punzalan, and T-Kay Sangwand state, "builds a critical stance regarding the role of archives in the production of knowledge and different types of narratives, as well as identity construction," specifically by utilizing critical theory as a central component to analyze systems of power.[13] Likewise, disability studies places a critical lens on the ways in which disability is understood, shaped, and met within society and builds theories around embodied experiences and identity. Within these frameworks, this dissertation addresses the ways in which we can consider disability in history through archives and archival material even through its absence. By developing a framework of a *crip provenance,* which I illustrate in the following chapter, this dissertation focuses on the multiplicity of relationships that can be considered when addressing archival materials. A crip provenance—a disability-centered method of resisting a rehabilitative orientation to fonds and instead, emphasizes meeting archival materials where they're at—first critiques the directionality of *provenance*, or the emphasis on the origin, history and custody of a record or fonds. Through

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[13] Michelle Caswell, Ricardo Punzalan, and T.-Kay Sangwand, "Critical Archival Studies: An Introduction," *Journal of Critical Library and Information Studies* 1, no. 2 (June 27, 2017), https://doi.org/10.24242/jclis.v1i2.50; Tonia Sutherland, "Archival Amnesty: In Search of Black American Transitional and Restorative Justice | Journal of Critical Library and Information Studies," *Journal of Critical Library and Information Studies* 1, no. 2 (June 2017), https://journals.litwinbooks.com//index.php/jclis/article/view/42.

such a critique, which acknowledges the messiness of archival realties, a crip provenance places focus on the new relationships and proximities that are established because they are always already dispersed, duplicated, and incomplete, facilitating an expansive re-reading of archival absences, partialities, and biases. My aim for this dissertation is to look at the broad application of disability studies to archival studies through the amplification of voices of disabled writers, scholars, and artists, while acknowledging that those voices, and many like them, have been affected disproportionately by the violence of archives throughout history.

Stylistically, throughout this dissertation I choose to situate myself within two worlds. I choose to use "we" as both a queer, non-binary Disabled person, affected by forms of oppression; and as a white archivist, a participant in oppressive systems, while acknowledging that my experiences are not universal to the disabled or archival communities. Within the chapters that use the interview data, I also use 'us' and 'we' as I identify with many of the findings and have experienced similar phenomena in archives, however when interviewees words are specific to their identities and life experience, I resist universalizing experiences.

Chapter Layout

Chapter One: "Towards a Crip Provenance" builds a theoretical lens for addressing the messiness of archival realities through describing the records that document the WCE. Through defining a crip provenance—a disability-centered framework of resisting the desire to restore and instead meets records where they are at to acknowledge all of the new connections and relations that are created because records are always already dispersed, duplicated, and partial—I draw attention to four central facets of archival and crip relationships: people, systems, materials, and spaces. In illustrating these connections, instead of trying to return to a former (often fictitious)

whole, a crip provenance allows us to talk about disability in relation to history, even if there's no archival evidence. The structure of the rest of this dissertation mirrors the four relationships that can be considered through a crip provenance: people, systems, materials, and space. Each of the chapters that follow will take one of these concepts and attempt to realize it in both a disability and archival sense in order to show the multifaceted connections that are created through and because of a crip provenance. Each chapter also includes a review of relevant literature. Together these chapters demonstrate how a crip provenance opens up multiple avenues for addressing disability in history—from highlighting moments of living disabled people experiencing archival material and spaces to expansive tangential histories that connect language and materials to politics and ableism within the history of the Field Museum.

Before diving into each of the four facets of crip provenance, Chapter Two: "Methodology & Methods" describes my research design, the histories and selection of my methods, and how I've implemented them. This chapter describes the overarching methodology of theory construction for this dissertation. I describe this methodology and how theory and practice are intertwined within archival studies and disability studies. Under this methodology, the data for this dissertation was collected using two different methods: semi-structured interviews and archival research, each of which is used in two of the following chapters. The interviews (used in Chapters Three and Six) allow for this project to begin and end with living disabled communities—in creating a historical project about disability, I couldn't think of history in isolation but felt compelled to include how it has shaped and shapes disabled people's lives today. Chapter Two describes my data collection methods for semi-structured interviews as well as my historical-archival research in pursuing disability in history (used in Chapter Four and Five). I will describe the selection of my sites and materials as well as my processes of data

analysis and the limitations of this study. These two techniques of data collection have been intentionally selected, as a theoretical sampling, to think through the complexities of misrepresentation and erasure; one (interviews) specifically looks at the effect, affects, and needs of the disabled community and the other (archival research) builds theories around contending with such impacts in archival materials around the history of the Field Museum.

Chapter Three: "'It felt like everything': A perverse absent-presence and the creation of archival interdependence" takes up the first facet of crip provenance: *people*. Using data collected through semi structured interviews with 10 disabled scholars, artists, activists and community members, Chapter Three investigates the impact of archival representation, misrepresentation, and erasure on living disabled people today. The data illustrates a complex affect relationship with archival documentation as well as a need for more complex representation. This chapter shows not only the complex affective relationships that disabled people have with being misrepresented, underrepresented, and erased in archival material, but also the interdependence and feeling of community with disabled people across time. This chapter, by illustrating the ways in which disabled people use and are affectively impacted by and feel in community with archival materials, demonstrates a fundamental aspect for the following chapters of this dissertation to build upon. By centering the needs of disabled people to see themselves represented with more complexity, as well as the complicated ways in which they relate to misrepresentation and to erasure, I aim to show the deep affective connections of living disabled people to each other.[14] This research demonstrates the necessity for disabled people to see themselves in history and underscores how disabled people can feel a deep sense of

[14] After all 10 interviews were complete, I emailed each participant to get their consent to connect them as a cohort. Currently, 8 out of 10 participants have been connected with one another via email, and all participants will have a chance to read and edit any work I produce from the interviews before it is published.

community not only with current communities, as a diverse community with multiple intersecting identities, politics, and opinions—which is so vital to our existence—but also with disabled people across time, thus illustrating and developing the term *archival interdependence*. Therefore this chapter shows how a crip provenance lens draws attention to *people*: not only creators, subjects, and archivists but also the people who experience, interpret, and are impacted by records across time. It lays the foundation for the rest of the dissertation by illustrating the need for a *political activation of archival material* through the development of robust critical and theoretical frameworks for archivists and archival users alike.

The next two chapters take a more theoretical and historical turn, using the historical-archival data I've collected through investigating the history of the Field Museum in response to the disabled communities need for more complex representation. Chapter Four: "Archival assemblages: applying disability studies' political/relational model to archival description" turns to the concept of *systems* and the power of language, by investigating the proximities of archival description. This chapter critically explores power structures embedded in archival description and re-conceptualizes archives and archival material as assemblages of politicized decisions specifically by utilizing Alison Kafer's political/relational model of disability as a framework. Kafer's model draws upon previous models of disability to open up contestation and politicization of disability as a category. This approach acknowledges that concepts of disability always already intersect with notions of race, class, age, gender, and sexuality. This chapter argues that crossinforming archival studies and feminist disability studies illuminates the long history that records creation and description processes have in documenting, surveilling, and controlling disabled and other non-normative bodies and minds. Furthermore, a political/relational approach makes possible the illumination of *archival assemblages*: the

multiple perspectives, power structures, and cultural influences—all of which are temporally, spatially, and materially contingent—that inform the creation and archival handling of records. Through a close reading of a circular, "The International Congress of Charities, Correction and Philanthropy" produced as part of the WCE and its description within an archives, this chapter focuses on the complexity of language and its politics within disability communities. I identify the interconnected systems that produced categories such as "delinquents", "criminal", "insane", "feeble-minded", and "pauperism" while also drawing attention to the simplification of this record in the online finding aid. A political/relational approach first promotes moving away from the replication and reliance on "self-evident" properties of a record and second, advocates for addressing—not redressing—contestable terms, both of which illuminate the archival assemblages which produced it. Moreover, by tracing the histories of a museum object, this chapter not only problematizes a wide array of descriptions that rely on the 'self-evident' but also shows how such lenses can highlight a multiplicity of connections to disability, even when it is not readily apparent in records. By embracing the contestation of disability, and therefore the corresponding ways in which it is represented in archives, archivists and archives users are able to perceive and challenge the ways in which norms and deviance are understood, perpetuated, and constructed in public narratives via archives. This chapter builds theory around archival description and shows how a crip provenance can not only highlight the *systems* that produced a single record or fonds, but also all of the interlocking systems that created and influenced the creation of other records, entangled with legislation, archival processes, attitudes, and records across time.

Moving even further outward, Chapter Five: "Chemical Assemblages: Locating Disability in History & the Materiality of Labor" traces proximities of *materiality* in order to tell

a history of disability, even when there is no evidence. By tracing the archival, museum, and alternative uses of *naphthalene*, one chemical used for the preservation of materials in the Field Museum, this chapter illuminates how a disability studies lens allows me to talk about disability and ableism when there is little or no obvious evidence of disability in history. I investigate a plethora of material connections to disability by tracing naphthalene's historical uses in natural history museums, like the Field Museum, as well its alternative uses in domestic spaces. Through tracing naphthalene's toxic properties, alternative uses, and historical facets, I illuminate parallel histories of feminized labor and center disability in a conversation that historically has left it out. This chapter builds theory around natural history and utilizes queer phenomenological approaches to draw attention to that which has been accepted as standard practice and thinks through the politics of exposure. It demonstrates the power of a crip provenance framework in re-centering disability through materiality, when archival evidence is lacking. In building towards a crip provenance, considering *materials*—not just those which are present in the record itself, but the parallel histories and practices—I make discussing disability and ableism possible when they are not apparent. Moreover, this framework makes addressing colonial values apparent in spaces and materials where they might not be obvious, such as within non-human animal or botanical collections.

Chapter Six: "'It wasn't necessarily designed with that experience in mind': The Affect of Archival (In)Accessibility & 'Emotionally Expensive' Spatial (Un)Belonging " returns to living disabled communities and the power of their words in illustrating their relationships and proximities to archival *spaces*. Disabled people have long emphasized the ways in which spaces impact their daily lives—from accessible buildings to academic institutions. As the theme of accessibility emerged organically from the interview data, this chapter draws out the ways in

which archival spaces and their in/accessibility affectively impact disabled archival users. As physical spaces embody and reflect social relations through which one can feel understood or included, this chapter asks: how do disabled researchers experience accessibility and/or inaccessibility in physical and digital archival spaces? And what affects, emotions and feelings around in/accessibility impact disabled researchers' archival experiences? First, participants highlighted how many disabled people do not have access to archives or other academic institutions. This foregrounded the awareness that participants had around their privileges in being able to do archival work and produced some anxiety around being grateful for their privileges. Second, disabled archival users described how they experience barriers to accessibility not only at a fundamental level—of physically being able to get into a building or archives room—but also through archives' policies and the ways in which archival work is expected to be done. These experiences of navigating inaccessibility show the overwhelming prevalence in the ways that archival spaces can be inaccessible to disabled patrons, which sets the stage for the final finding. The varying levels of inaccessibility—the ways in which accessibility is implemented and materials are treated—greatly impact how disabled researchers feel disabled people are valued and feel a sense of belonging in archival spaces. I illustrate different affects, such as a sense of the devaluation of accessibility and disability as an organizing category being "part of the trash," deprioritized, and erased. Through these affects, I develop the term "emotionally expensive" to emphasize how the prevalence of archival inaccessibility comes at a great cost to disabled archival users, not only producing a sense of unbelonging but also often preventing them from using archives. These unintended findings, emerging out of the data, demonstrate how central accessibility is to disabled people's lives—it is almost impossible to talk about our experiences of spaces, materials, and technologies without

discussing how we navigate the multiple barriers to access them. The final facet of *spaces* emphasized the histories of and affective ways in which accessibility is interwoven into all of the previous aspects—how people, systems, materials, and spaces all embody values that shape how disabled people experience archives.

To conclude the dissertation, "Disability and Its Absence" returns to the literature that inspired this dissertation project—I address the contributions of this research to both archival studies and disability studies. Through developing a crip provenance, this dissertation has shown how we can complicate disability in history and consider a multiplicity of people, systems, materials, and spaces as they add context to records: as disabled people experience records (Chapter Three), archivists accession, describe, process and them while considering how and why they were produced (Chapter Four), archival labor and exposure to toxic materials have parallel histories that can be connected to disability (Chapter Five), and all of those facets are bound up in how spaces are used, experienced, and accessed (Chapter Six). This framework for provenance contributes to the field of archival studies as a way of resisting orienting backwards, letting go of the attachments to a previous whole, and instead creatively intervening outward. It provides an expansive way for archivists to consider a wide range of materials and histories in relation to records as part of provenance, while also providing a critical lens for how to re/introduce disability in records where it is subtle or absent. I also discuss how this research also contributes to methodologies within disability studies by drawing attention to the archival decisions made in the very materials we use to tell our histories. Furthermore, as this research places focus on archival absences—how we can read disability into history entirely *outside of the*

archival grain[15]—as an expansive way of looking elsewhere, as well as contributes to thinking about the unique experiences and needs of disabled archival users.

What these chapters do collectively is illustrate a constellation of connections through disability: of disabled people to each other—across time and space—and of disabled people to the archives that impact how we understand the history of disability and history of natural history. This dissertation is not at all about placing blame on archivists—I acknowledge there is only so much we can do to intervene with historical records—rather, my aim is to provide a framework that may help us resist 'fixing' archival material (or assuming that we can) and instead provide creative ways to move forward. Douglas Banyton tells us that "Those of us who specialize in the history of disability, like the early historians of other minority groups, have concentrated on writing histories of disabled people and the institutions and laws associated with disability." He continues, "It is time to bring disability from the margins to the center of historical inquiry."[16] Answering this call I want to train a critical lens on the very materials we use to re/tell history and develop a new theoretical framework, a crip provenance, for reading along, against, and outside of the archival grain. To tell a story when there's little or no evidence, as I will demonstrate in this dissertation, involves meeting archival materials where they are at—acknowledging that there is so much we can never know, while thinking through creative interventions to grappling with the impossible nature of archives and the materials they hold.

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[15] Marisa J. Fuentes, Dispossessed Lives: Enslaved Women, Violence, and the Archive (Philadelphia: University of Pennsylvania Press, 2016); Saidiya V. Hartman, Scenes of Subjection: Terror, Slavery, and Self-Making in Nineteenth-Century America, 1 edition (New York: Oxford University Press, 1997).

[16] Douglas Baynton, "Disability and the Justification of Inequality in American History," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky (NYU Press, 2001), 33–57, 52.

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Chapter One: Theoretical Framework
Towards a Crip Provenance

Introduction

As I began archival research for this dissertation, looking for traces of disabled people, I was confronted not only with the lack of evidence but also with the messiness of archives that impacted my ability to locate records. Located at several different archives, the materials that document these histories were created by multiple people—tourists, exhibitors, museum curators, etc.—governing bodies, and entities. Materials are not only dispersed across different sites—all of which have varying levels of accessibility—but are also duplicated, organized according to different schemas, and described in different ways, with varying amounts of detail in finding aids. In other words, the documentation of these events are not a single (or even a few), 'clean' archive(s). Confronting the reality of archival material—where materials are dispersed, duplicated, or absent—as well as the lack of archival documentation on disability, I began to think about what archives sometimes can't give us and the frequency with which archives are messy or incomplete. As an archival studies student, I am trained to think not only about the *contents* of the records—if and how I could perceive disabled people of concepts of disability—but also the *context* of records—how the decisions made in archives impact my experience of records. But what do we do when content is lacking or context is messy? Drawing on archival and disability theories in response to this archival reality, I acknowledge the prevalence of messy or incomplete archives and develop a framework for contextualizing records in new ways to tell this history with disability at the center.

Concepts in archival studies such as the archival bond, respect des fonds, provenance, and original order all give *context* to fonds—records that originate from the same source—by

emphasizing the history of records: the decisions made that illuminate how they have arrived in an archives. The concept of *the archival bond*—what Luciana Duranti defines as "the network of relationships that each record has with the records belonging in the same aggregation,"[1] —"places a record in context and gives additional meaning to the record."[2] Laura Millar defines "*Respect des fonds* is the principle that the records of one particular creator are kept together, in their original order, as an organic unit. And that unit was defined by its *provenance*: the person or persons, family or families, and corporate body or bodies that created and/or accumulated and used records in the conduct of their personal or business life."[3] Considering the archival bond, provenance, respect des fonds and original order, archivists pay close attention to the history of a record, in relation to a fonds, archival processes, and "the development of the activity in which the document participates."[4] So in tracing the history of the Field Museum I also trace the history of these records—who created them, where they moved, how they came to be where they are today—to draw attention to the archival decision-making that influences how we understand history. In confronting this archival reality, I describe the messiness of archival material, and the impossibility of constructing a straightforward provenance. However, what this archival reality—or realities—does do is serve as a foundation for redefining archival approaches to telling history. As I will describe, it was *because* these materials were dispersed, duplicated, and

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[1] Duranti, Luciana. "The Archival Bond." *Archives and Museum Informatics* 11, no. 3 (September 1, 1997): 213–18. https://doi.org/10.1023/A:1009025127463, 215-6

[2] The Society of American Archivists, "Archival Bond," A Glossary of Archival and Records Terminology, The Society for American Archivists, accessed November 21, 2018, Neutrality, social justice and the obligations of archival education and educators in the twenty-first centuryhttps://www2.archivists.org/glossary/terms/a/archival-bond.

[3] Laura Millar, "The Death of the Fonds and the Resurrection of Provenance: Archival Context in Space and Time," *Archivaria* 53, no. 0 (January 1, 2002): 1–15, 4.

[4] Luciana Duranti, "The Archival Bond," *Archives and Museum Informatics* 11, no. 3 (September 1, 1997): 213–18, https://doi.org/10.1023/A:1009025127463, 217.

processed in different ways that I could perceive new relationships of disability to archives and grapple with what might never have been a ‘complete picture’ of disabled people in history.[5]

As I started archival research around the history of the Field Museum, I ended somewhere else entirely: my experiences looking for disability in history—and often not being able to find it—was incredibly emotional. My embodied experience as a Disabled person navigating archival spaces and researching disability led me to consider not only the connections of records to histories, archives, and their context, but also to myself and other living disabled people. Therefore, while the framework I develop in this chapter is centered around the archival realities of the World’s Columbian Exhibition (henceforth abbreviated as WCE) material, I also expanded my methods to take into consideration the experience of witnessing in history as part of what gives records context. In response to thinking about the ways in which records are related to each other, to history, and to the archival decisions made around them, I broadened this research to include interviewing disabled people on their experiences in archives, as a way of considering the new relationships that are formed (between living disabled people and records) because records are dispersed and experienced.

Drawing attention to how many archivists work to reconcile records that have been moved, rearranged, and dispersed, to *reconstruct* a fonds, this chapter highlights the ‘curative’ and ‘rehabilitative’ orientations of provenance. Put in conversation with disability studies scholarship—which critiques rehabilitating, curing, and restoring—the concept of provenance can be radically refigured, placing less emphasis on ‘fixing’ or reconstructing a fonds (which might have never been in the first place), and instead addressing the reality of archival material to acknowledge the *new* relationships created *because* they are always already fragmented. With

[5] My goal isn't to suggest that a complete picture is even possible, but to highlight, through grappling with the inevitable partialities of archival representation, we can create more complicated histories and narratives.

this critical lens, this chapter lays the theoretical scaffolding of a *crip provenance*: a method of resisting a rehabilitative orientation to fonds—trying to reconstruct a straightforward, 'clean' archive—and instead, emphasizes meeting archival materials where they're at. Acknowledging archival realties places focus on the new relationships and proximities that are established because they are always already dispersed, duplicated, and incomplete, which can facilitate an expansive re-reading of archival absences, partialities, and biases. In this chapter I will bring together different conversations on relationality—both of archives and disability—in order to expand and reorient provenance.

In this chapter, I will first describe an overview of the records that document the history of the Field Museum and the World's Columbian Exhibition, drawing attention to the varying provenance of the materials and the archives in which they were found. Then, I'll describe how concepts such as provenance, respect des fonds and the archival bond have historically maintained historical structures of power while simultaneously adding context to records—where they've been, how they've been moved. Next, by foregrounding disability studies literature and paralleling this archival reality, I will build on current critiques of provenance and challenge rehabilitative orientations to restoring a fonds. Through this framework, I'll build towards a *crip provenance*, which meets records where they are at and acknowledges all of the new connections and relations that are created because records are dispersed, duplicated, and partial. In doing this work, I'll do my best in describing the history of the World's Columbian Exhibition, the museum and the records that document them, but this is in no way a complete or objective picture. Instead, I hold the many levels of impossibility of this project at the fore—to grapple with archival erasure is to simultaneously attempt to tell an impossible history while realizing that such efforts will never be complete.

I intentionally use the word "crip", which was defined by Carrie Sandahl as "cripple, like queer is fluid and ever-changing, claimed by those whom it did not officially define."[6] Like the term "queer", "crip" has been reclaimed as a political identity by many disabled people. Nancy Mairs saliently states, "People—crippled or not—wince at the word 'crippled' as they do not at 'handicapped' or 'disabled.' Perhaps I want them to wince."[7] And Eli Clare emphasizes this term as "words to shock, words to infuse with pride and self-love, words to resist internalized hatred, words to help forge a politics"[8] My choice to think through the subtleties of disabled people in history is one based in crip theory, a subset of disability studies.[9] Crip theory is also informed through feminist epistemologies, queer theoretical approaches, and the ways in which other identities intersect and complicate disability.[10] Alison Kafer expands a crip theoretical approach to include "those who lack a 'proper' (read: medically acceptable, doctor-provided, and insurer-approved) diagnosis for their symptoms" as well as "people identifying with disability and lacking not only a diagnosis but any 'symptoms' of impairment."[11] Such a crip theoretical approach to historical materials allows me to think through disability in history where: disability intersects with other identities that complicate disabled experiences, disability might not be named, someone might not identify as disabled but still be impacted by forms of ableism, or disability might be absent altogether.

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[6] Carrie Sandahl, "Queering the Crip or Cripping the Queer?: Intersections of Queer and Crip Identities in Solo Autobiographical Performance," *GLQ: A Journal of Lesbian and Gay Studies* 9, no. 1 (April 10, 2003): 25–56, 27.
[7] Nancy Mairs, *Plaintext: Essays*, Reprint edition (Tucson: University of Arizona Press, 1992), 9.

[8] Eli Clare, Dean Spade, and Aurora Levins Morales, *Exile and Pride: Disability, Queerness, and Liberation*, Reissue edition (Durham: Duke University Press Books, 2015), 84.

[9] Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: NYU Press, 2006).

[10] Sami Schalk, "Interpreting Disability Metaphor and Race in Octavia Butler's 'The Evening and the Morning and the Night,'" *African American Review* 50, no. 2 (July 21, 2017): 139–51, https://doi.org/10.1353/afa.2017.0018.

[11] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 12-13.

Records' Reality

I want to first address the reality of the records that document the history of the Field Museum as a way to illustrate how provenance can or cannot be known in different ways. Archival theory is formed around the practices and policies of archives and archivists—theory and practice are deeply intertwined. Thus turning to the reality of these records will not only ground the theory I build in practice, but also, help me demonstrate that critiquing traditional approaches to provenance might highlight the inevitabilities of archival research and archival work. Tracing the history of the records that document the Field Museum and the World's Columbian Exhibition (WCE) proved to be a tricky endeavor: records were created by multiple individuals, organizations or governing bodies, they were duplicated for different purposes, and dispersed across different archives with various levels of description as well as documentation of their individual histories. To illustrate this messiness, I focus solely on WCE records—instead of the entire history of the museum—as a contained event that is represented in archival material. My description of this archival reality is mediated not only through my witnessing records at multiple archives—addressing their *contents*—but also through generous conversations with archivists, who recalled and investigated institutional memory and gave me access to provenance files, facilitating my understanding of their *context*. Through addressing the history of these records, I will demonstrate that traditional provenance might be incommensurate with some archival realities—especially around disability—where content and context are often incomplete, and therefore spurring this dissertation's major question: "how we can tell a history of disability when there is little or no archival evidence?"

The materials documenting the WCE and the history of the Field Museum were created by a wide array of individuals, organizations, and governing bodies. Visitors to the WCE took

photographs, sent postcards, and journaled about their experiences at the fair and created multiple types of documentation of their experiences. For example, governing bodies, such as The Women's Board documented their exhibits, finances, and participation within the aspects of the fair that they were involved in, and individuals, like amateur photographers, took photos of exhibits. Charles Dudley Arnold, hired by the Fair's Director of Works, Daniel H. Burnham, was the official photographer of the fair. Arnold documented many buildings, exteriors, iconic structures and sculptures, and waterways through the fair's construction, opening, and closing. These photographs complimented the many maps, brochures, and advertisements that were also produced for the WCE. This historic event was recorded through many different lenses, from individuals who had the financial means to photograph their experiences, exhibitors who itemized expenses, and the World's Columbian Exposition Commission, who planned, organized, and documented the fair. And much of the WCE documentation does not exist in singularity; many records were reproduced for multiple purposes and various people and organizations documented similar aspects, creating almost indistinguishable records.

After the fair, fonds were divided, often (but not always) by topic and creator, and materials deemed valuable were accessioned into different archives, libraries and special collections. Yet addressing the physical location and provenance of fonds created around the WCE became an almost impossible task. Currently, the records that document the formation of the Field are located in various repositories—arguably too many for one person (namely, one Disabled graduate student who financially and physically cannot travel multiple times to multiple cities in the process of writing a dissertation) to visit. Through looking at documentation, personal papers, and provenance files as well as through generous conversations with multiple archivists, I found part of the history around which records went where. Some fonds, such as

Arnold's photographs, for example, are dispersed across multiple archives: I looked at hundreds (if not thousands) of his photographs as part of the "Charles Dudley Arnold Photographic Collection" at the Chicago History Museum Research Center and the "C. D. Arnold Photographic Collection" at Harold Washington Library Special Collections, and duplicate or similar collections are also housed in the Art Institute of Chicago Archives, University of Chicago Photographic Archives, and Columbia University Libraries Archival Collections, not to mention as part of books, printed as postcards, and duplicated as illustrations. Other creators' papers and personal collections were designated to specific archives based on their profession. For example, the Art Institute of Chicago has much of the architectural and art related materials, such as Burnham, Daniel H., Jr. and Hubert Burnham Papers, which documented some of the WCE building as well as their other architectural endeavors. The John Crerar Library, located at The University of Chicago, was the repository for many of the scientific publications, whereas Chicago Public Libraries houses materials for public library functions, some publications and ephemera, which is divided among the Chicago public libraries, and Harold Washington Library Special Collections, respectively. Through this agreement, The Newberry Library was designated for most of the humanities related materials such as "literary, musical and dramatic history, publishers' and literary reviews and printing." And there are a number of other libraries, archives and special collections that store individual records, fonds, papers, and ephemera documenting the WCE and the Field—such as the University of California Los Angeles Library Special Collections, Seaver Center for Western History Research at The Natural History Museum of Los Angeles County, Case Western Reserve University, University of California San Diego Special Collections and Archives, Environmental Design Archives, University of

California Berkeley—much of which was donated by individuals, but others which have no provenance records available online.

Addressing how all of these records are organized and described is a completely other overwhelming undertaking. Some fonds were kept together as they moved to different archives, while many others were divided or assembled in 'artificial collections' often by the topic of the WCE. These varying organizing schemas highlight the varying levels of documentation of provenance: what was originally documented, how records moved, traveled, and were dispersed, discarded, and rearranged. Given these varying places and organization levels, the materials that represent the WCE have differing levels of accessibility and transparency about what records or fonds each archive has. Currently, the Field Museum's archival material is documented in a spreadsheet that is not publicly available. Archivist Armand Esai told me he uses "minimal description in an excel spreadsheet" using MARC categories to document the archives' holdings. He, along with interns, visiting researchers, and volunteers, also work to make finding aids, some of which are available online. Other archives that I visited, such as the Chicago History Museum Research Center Archives, had more robust finding aids and online databases, documenting some fonds at item-level and others at fonds-level. Although I could access much of this material—through knowledge of navigating online resources, finding aids, and other archival processes—I wonder about all that I haven't. Conducting this research only drew my attention to the archives I have not visited because they *seem* to only have duplicates of records I've already looked at; or because they only have a few folders, which does not justify long distance travel; or because there is no online documentation of their holdings.

In describing these archival realities, I am doing my best to retell the messiness—and overwhelm—that I experienced in researching this history, while also trying to recount it from

my notes, photographs, emails, and memory. It is a flurry of records, stories, provenance files, follow up emails, rumors, institutional memory, and absences. And this experience of the many people, organizations, and bodies that produced selected, described, organized, and accessed records highlights a constellation of decision-making that impacts how we understand history. Moreover, it emphasizes the ways that records are not necessarily singular: many records are duplicated; strikingly similar documents exist; fonds are not always kept together; documentation of why and how decisions were made can vary; records are currently located across multiple archives; and fonds are processed at different levels. Therefore, in thinking of tracing a history of disability amongst these documents, I want to center the history of these records, and next turn to how archivists have grappled with provenance and giving records context.

Archival Context & Provenance

While I've loosely described some pieces of provenance from the WCE records, I want to delve a little deeper into how archival scholars have defined and utilize provenance as a way to illustrate the history of a record. This section first addresses more traditional, singular notions of provenance and then highlights how it has been expanded and critiqued. Against the background of the archival realities I've already outlined in the context of researching the WCE, I will surface the undertones to restore provenance—a desire for a whole, compete historical picture—which are in stark contrast to these (and many) archival realities, when provenance is messy, partial, incomplete, or nonexistent.

Although archivists now are acknowledged as active participants who shape and are shaped by history, they have been depicted as neutral custodians of records in dominant Western archival theory, and concepts such as provenance and original order are likewise meant to

objectively preserve context.[12] Much of this tradition can be traced back to what is known as The Dutch Manual of 1898, which proposes a rule of original order, adopted from the Association of Archivists, where "The system of arrangement must be based on the original organization of the archival collection,"[13] as it is "the most important of all, because in it is formulated the fundamental principle from which all other rules follow."[14] Shortly thereafter Sir Hilary Jenkinson developed another tome, defining aspects of archival theory and practice. Similarly focusing on administrative records, he states, "our aim must be to get back to the original order designed for our Archives by their compilers."[15] These two foundational works, amongst others like T.R. Schellenberg[16] and Margaret Cross Norton,[17] influenced much of archival scholarship and practice around the world.[18] Much of this literature illustrates processes such as provenance, original order, and description as apolitical, where an archivist, unbiased, can make the "right" decisions of what records to select for an archives and how to describe, store, and maintain them for future use.[19] This traditional Western mindset seeks to ensure that documents are "properly"

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[12] For a historical tracing of provenance, see: "The Last Dance of the Phoenix or The De-Discovery of the Archival Fonds," *Archivaria* 54, no. 0 (January 1, 2002): 1–23.

[13] Samuel Muller, Johan Feith, and Robert Fruin, *Manual for the Arrangement and Description of Archives* (New York :, 1940), http://hdl.handle.net/2027/mdp.39015005389211, p. 52.

[14] Samuel Muller, Johan Feith, and Robert Fruin, *Manual for the Arrangement and Description of Archives* (New York :, 1940), http://hdl.handle.net/2027/mdp.39015005389211, p. 52.

[15] Hilary Jenkinson, *A Manual of Archive Administration* (London : P. Lund, Humphries & co., ltd., 1937), http://archive.org/details/manualofarchivea00iljenk, 104.

[16] T. R. Schellenberg, *Modern Archives Principles and Techniques*, 1st edition (Chicago: The University of Chicago Press, 1956).

[17] Margaret Cross Norton, *Norton on Archives: The Writings of Margaret Cross Norton on Archival & Records Management* (Southern Illinois University Press, 1975).

[18] Terry Cook, "What Is Past Is Prologue: A History of Archival Ideas Since 1898, and the Future Paradigm Shift," *Archivaria* 42, no. 0 (February 12, 1997), http://archivaria.ca/index.php/archivaria/article/view/12175.

[19] Luciana Duranti, "Archives as a Place," *Archives and Manuscripts* 24, no. 2 (March 2007), 445-466.

ushered into an archives and, whilst maintaining a professional neutral role, an archivist "ensures that *relevant* documentation survives."[20]

At the present moment, provenance and original order remain central to archival theory and practice. Luke Gilliland-Swetland highlights how advocates for provenance often believe it to be an "'objective' alternative method of description, based upon arrangement, in contrast to the 'subjective' classification schemes."[21] Yet, by centering a critical lens challenging the filiopietistic aspects of provenance and original order, scholars have shown how provenance and original order can benefit the archival profession because they foreground the *context* of records. Jeannette Bastian, for one, states "The content, context and structure of record creation [are] inextricably bound together in a vision of provenance and community that seeks, weighs, and accommodates all the voices of a society."[22] Advocating archivists to expand the scope of provenance to include those historically excluded such as subjects and communities represented in records (as opposed to just records' creators), Bastian transforms provenance into a tool for community inclusion to elevate voices of those historically silenced. Joe Wurl complicates traditional notions of provenance by incorporating ethnicity and cultural groupings to challenge traditional hierarchies and values of ownership and custody. He highlights ethnicity as social, relational, dynamic, and mutable—not predetermined or static—which produces a sort of "cultural provenance." Through this lens, custodianship is replaced by stewardship, which allows

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[20] Mark Greene, "A Critique of Social Justice as an Archival Imperative: What Is It We're Doing That's All That Important?," *The American Archivist* 76, no. 2 (September 1, 2013): 302–34, doi:10.17723/aarc.76.2.14744l214663kw43, 328, emphasis mine.

[21] Luke Gilliland-Swetland, "The Provenance of a Profession: The Permanence of the Public Archives and Historical Manuscripts Traditions in American Archival History," *The American Archivist* 54, no. 2 (April 1, 1991): 160–75, https://doi.org/10.17723/aarc.54.2.w42580v137053675, 161.

[22] Jeannette Allis Bastian, "Reading Colonial Records Through an Archival Lens: The Provenance of Place, Space and Creation," *Archival Science* 6, no. 3–4 (December 1, 2006): 267–84, https://doi.org/10.1007/s10502-006-9019-1, 269.

for a “kind of symbiotic, ongoing ‘ownership’ connection between archive and originator,” that “cultivate[s] an openness of thought to how ethnic community life is actually transacted, through communication structures that might not be familiar to the shelves of our repositories.”[23] Therefore archival material is “viewed less as property and more as cultural asset, jointly held and invested in by the archive and the community of origin.”[24] Along these lines, Chris Hurley proposes “parallel provenance,” where two different claims of the origins of records can be held in tension: one tracing back to colonizers who created the records, and one that traces the colonized subjects, which, in tandem, work to recognize and complicate history.[25] And Terry Cook emphasizes that “A redefined sense of provenance [that highlights dynamic relationships with a creating or authoring activity] also offers archivists, their sponsors, and their researchers a means to stop drowning in an overwhelming sea of meaningless data and to find instead patterns of *contextualized knowledge*, which in turn leads to the hope for *wisdom and understanding*.”[26] Correspondingly, Tom Nesmith conceptualizes the “history of the record” as central to provenance as well as the notion of “societal provenance,” where “people play a role in *causing* the record we see today to *exist*. Their actions all have societal drivers, contexts and impacts as

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[23] Joel Wurl, “Ethnicity as Provenance: In Search of Values and Principles for Documenting the Immigrant Experience,” *Archival Issues* 29, no. 1 (2005): 65–76, p. 72, 69.

[24] Joel Wurl, “Ethnicity as Provenance: In Search of Values and Principles for Documenting the Immigrant Experience,” *Archival Issues* 29, no. 1 (2005): 65–76, 72.

[25] Chris Hurley, “Parallel Provenance [Series of Two Parts] Part 2: When Something Is Not Related to Everything Else.,” Archives and Manuscripts 33, no. 2 (November 2005): 52.

[26] Terry Cook, “What Is Past Is Prologue: A History of Archival Ideas Since 1898, and the Future Paradigm Shift,” *Archivaria* 42, no. 0 (February 12, 1997), http://archivaria.ca/index.php/archivaria/article/view/12175, 48, emphasis mine.

well."[27] The concept of provenance has been expanded to think about the context of records and how multiplying context can facilitate reckoning with the past.

Expanding provenance, as the aforementioned literature demonstrates, facilitates what's considered when thinking about the history of a record—parallel, secondary, and multiple histories. Yet, scholars have been critical of locating, restoring, and preserving the original organizational structure of a fonds. Jarett Drake, for one, critiques the ways in which archival processes such as provenance are never neutral and risk the preservation of harmful structures. He explains, "provenance… is at once a relic of the colonial and imperial era in which it emerged and also an insufficient principle to address the technical challenges of born-digital archival records and the social challenges of creating a radically inclusive record."[28] He illuminates that provenance is "a blunt, unforgiving, and impatient object that has a predetermined if not precarious path… that thrives with the presence of a clear creator or ownership of records and with a hierarchical relationship between entities, both of which reflect the bureaucratic and corporate needs of the Western colonial, capitalist, and imperialist regimes in which archivists have most adhered to the principle."[29] Provenance, as Drake critiques, influences archival descriptions and colonial, patriarchal, and Western ideals are thus perpetuated instead of addressed. In other words, the original order, provenance, and

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[27] Tom Nesmith, "What's History Got to Do With It?: Reconsidering the Place of Historical Knowledge in Archival Work," *Archivaria* 57, no. 0 (January 1, 2004): 1–27; Tom Nesmith, "The Concept of Societal Provenance and Records of Nineteenth-Century Aboriginal–European Relations in Western Canada: Implications for Archival Theory and Practice," *Archival Science* 6, no. 3 (December 1, 2006): 351–60, https://doi.org/10.1007/s10502-007-9043-9.

[28] Jarrett M. Drake, "RadTech Meets RadArch: Towards A New Principle for Archives and Archival Description," Medium, *On Archivy* (blog), April 6, 2016, https://medium.com/on-archivy/radtech-meets-radarch-towards-a-new-principle-for-archives-and-archival-description-568f133e4325#.rxi38ik03.

[29] Jarrett M. Drake, "RadTech Meets RadArch: Towards A New Principle for Archives and Archival Description," Medium, *On Archivy* (blog), April 6, 2016, https://medium.com/on-archivy/radtech-meets-radarch-towards-a-new-principle-for-archives-and-archival-description-568f133e4325#.rxi38ik03.

foundational language of a fonds—developed to serve particular purposes (usually for the benefit of those who have historically had the power to create, preserve and organize records)— if not addressed, risk merely perpetuating power inequities.

Building off of these critiques, I am skeptical of working towards something that may not only risk perpetuating historical power inequalities, but also that may not even be possible—as outlined in the beginning of this chapter, records created around the WCE are dispersed, arranged, and processed in different ways, while having many unknowns of how they got where they are today. James Lowry highlights that archival theory is "a theory that privileges wholeness," where many work to reconcile with records that have been moved, rearranged, and dispersed, to *reconstruct a fonds*.[30] He continues, "This concern for wholeness stems from the fact that archives tell stories through their forms, structures and relations."[31] Along these lines, many of the aforementioned works on provenance carry an undertone that emphasizes original order or an original fonds, a desire for a whole: David B. Gracy echoes that archivists still tend to "lean toward 'restoration' work, toward maintaining, or reestablishing, the files as closely as possible to the order in which they were kept by the creator," giving context to materials to better understand history.[32] Even Millar, while critical of the ability for archivists to restore a fonds "that can never exist," still places emphasis on archival material as the "remains or records of all

[30]James Lowry, ed., *Displaced Archives* (Taylor & Francis, 2017), 1, emphasis mine.

[31]James Lowry, ed., *Displaced Archives* (Taylor & Francis, 2017), 1.

[32] David B. Gracy, *Archives & Manuscripts: Arrangement & Description*, Basic Manual Series - Society of American Archivists (Chicago: Society of American Archivists, 1977), https://catalog.hathitrust.org/Record/000748438.

records created, accumulated, or used by someone. They are the residue, the fragments that have been kept,"[33] which imagines a former complete fonds that once was.

Returning to the archival reality of the WCE records, the provenance of different fonds was not always known. Sometimes the provenance of a record was murky or vague. For example, Johanna Russ, Senior Archival Specialist at the Harold Washington Library Special Collections gave me access to provenance files for some of the WCE collection, a resource that is usually not available to researchers. Through these provenance files—and letters between archivists, secretaries, and the director of the WCE—I saw how some WCE materials were designated to go to the Chicago Public Library but then were decided to be housed in the Chicago History Museum, clearly outlining the provenance of certain fonds. In other instances, the provenance of a record was constructed through a combination of institutional memory and records—when I asked about the provenance of the Olson-Moore lantern slide collection at the Chicago History Museum Research Center Archives, archivist Lesley Martin investigated. Through talking to other archivists and digging into the database, she followed up with me through email, stating,

> Neither accession number is in the database of deeds…. Searching under the names Mae Olson and Tom Moore, I found that the database of deeds included their names, but with no accession numbers. Mae Olson, September 21, 1966, donating "6 boxes of slides and one book on the World's Columbian Exposition" (as well as "2 bottles of bath salts"??). Tom Moore donated "lantern slides (72) 3" x 4" views of the World's Columbian Exposition, prepared by Ira Chase" on September 17, 1973. So, these two separate donations were merged into one with a single accession number. (I should note that our

[33] Laura Millar, "The Death of the Fonds and the Resurrection of Provenance: Archival Context in Space and Time," *Archivaria* 53, no. 0 (January 1, 2002): 7.

current registrar was somewhat horrified at this—definitely not how this would be handled now).

And other times, the provenance would be completely unknown. This archival reality shows how provenance is often murky, sometimes vague or rumored, and, other times, is completely unknown. While I gained access to provenance files that depicted which materials were donated, purchased, or accessioned, other times the provenance of a fonds was only known through institutional memory, rumors, or often not at all.

Critiquing Provenance & the Desire for a Whole

As I've shown thus far, although provenance, original order and the archival bond provide some context to records, there's often so much we do not and cannot know about the history of a record. While provenance, when known, can provide context and history surrounding a fonds, I want to grapple with the reality that I was so often confronted with—when provenance is messy, partial, incomplete, or nonexistent. Building on Drake's critique, I ask not only "what is it we are restoring?" but also "can a fonds even be restored?" or "was it ever a whole fonds in the first place?" With this critique in mind, I want to train a critical lens on the *directionality* of provenance and the imagined former whole fonds. By focusing on archival metaphors that draw on bodily experience, I will bring in disability studies scholarship to talk about orientations to fixing and curing. By drawing such parallels, I will underscore disability studies' productive notions of relationality, and then will return to provenance to highlight that when emphasis is placed on restoring a former whole, archivists may overlook the impossible: that a 'complete' fonds may have never existed. As many archivists work towards restoring provenance, they

might overlook other ways of contextualizing records that can facilitate moments when there's scarce documentation.

Drawing attention to incompleteness, Lowry begins the introduction to the book, *Displaced Archives* by stating, "Archivists speak about the archives as a *body* - a corpus of records."[34] He continues, "From this perspective, the displacement of archives can be conceived of as the *disfiguration* of an organic whole -- the removal of a body part."[35] Jessica Lapp highlights how "Archivists are forever encountering bodies: bodies of records, bodies of knowledge, the disintegrating bodies of silverfish, bodily matter, bodily impressions, researchers, colleagues, volunteers, managers, rodents."[36] Jamie A. Lee imagines archives "as a body (and multiple bodies) of knowledge that, like the human body, is multiply situated with regard to identities, technologies, representations and timescapes."[37] This metaphor functions for Lee to think about archival materials, like bodies, as they "respond, shift, change, engage and become again and again."[38] Likewise considering actual bodies and bodily metaphors of archives, Zeb Tortorici proposes that "we think metaphorically about archiving as a mode of digestion," whereby we consume archival materials in a similar manner to how we consume "bodies [documented within records], emissions, and secretions of humans."[39] And Millar uses the term

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[34]James Lowry, ed., *Displaced Archives* (Taylor & Francis, 2017), 1, emphasis mine.

[35]James Lowry, ed., *Displaced Archives* (Taylor & Francis, 2017), 1, emphasis mine.

[36] Jessica M. Lapp, "'Handmaidens of History': Speculating on the Feminization of Archival Work," *Archival Science* 19, no. 3 (September 1, 2019): 215–34, https://doi.org/10.1007/s10502-019-09319-7, 225.

[37] Jamie A. Lee, "Be/Longing in the Archival Body: Eros and the 'Endearing' Value of Material Lives," *Archival Science* 16, no. 1 (March 2016): 33–51, https://doi.org/10.1007/s10502-016-9264-x, 38.

[38] Jamie A. Lee, "Be/Longing in the Archival Body: Eros and the 'Endearing' Value of Material Lives," *Archival Science* 16, no. 1 (March 2016): 33–51, https://doi.org/10.1007/s10502-016-9264-x, 40.

[39] Zeb Tortorici, "Visceral Archives of the Body Consuming the Dead, Digesting the Divine," *GLQ: A Journal of Lesbian and Gay Studies* 20, no. 4 (January 1, 2014): 407–37, https://doi.org/10.1215/10642684-2721375.

'dismembered fonds' to emphasize the remnants of a whole archival corpus.[40] While I'm critical of this metaphoric use of archives as bodies,[41] it does, however, open space for me to bring in disability studies and complex ways of relating to bodyminds. Disability studies scholar Sami Schalk, while critical of disability as a metaphor, highlights the importance of "the reading of disability metaphors as having multiple literal and figurative meanings, and a crip theoretical expansion of the category of disability as a material and discursive concept."[42] Drawing attention to "archives as a body" facilitates a turn towards disability studies, where we can unpack the concept of 'wholeness' and rehabilitation and also recenter the material realities of disabled people.

Many disability studies and disabled scholars are critical of the prominent orientation towards disabled bodyminds: despite the rise of disability studies scholarship and activism, disability continues to be predominantly conceptualized in medical terms and this, in turn, elicits misguided responses to how to solve the "problem" of disability. In this dominant framework, named *the medical model of disability*, disability is understood as a fixed, monolithic category

[40] Laura Millar, "The Death of the Fonds and the Resurrection of Provenance: Archival Context in Space and Time," *Archivaria* 53, no. 0 (January 1, 2002): 7.

[41] As I recognize the value in works that draw on the ways in which the histories of sickness and disability operate within archival systems, I simultaneously am cautious about the ways in which sickness, pain, and disability also get deployed metaphorically to draw on the negative aspects of archives. Especially in a dissertation that is drawing out concepts from sick and disabled experiences, I am wary about producing a similar slippage into metaphor. Susan Sontag critiques illness as a metaphor for romantic views of the world, which feeds into moral and actualized fears of illness, the idea that strong will can overcome illness just as any obstacle, and that illness should be met with military aggression, by "a rousing call to fight by any mean whatever a lethal, insidious enemy" (11). The ways in which such metaphors distort the lived experiences of pain, sickness, and disability often play on stereotypical tropes of disability as representing loss, lack, or in need of fixing, that reinforce the stigmatization of sick and disabled people.
Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, 1st edition (New York: Picador, 2001).

[42] Sami Schalk, "Interpreting Disability Metaphor and Race in Octavia Butler's 'The Evening and the Morning and the Night,'" *African American Review* 50, no. 2 (July 21, 2017): 139–51, https://doi.org/10.1353/afa.2017.0018.

comprised of self-evident facts and as a "by-product of the concept of normalcy."[43] The experience of being D/deaf, for example, is simplified to the "fact" that one cannot hear and that of being blind to the "fact" that one cannot see.[44] Simi Linton states that "the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy."[45]

When disability is considered a static character of the body or mind (not to mention a deficiency), it becomes not only a simplified "problem" to be fixed or normalized, but also an individualized problem. Linton states that "the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy".[46] Through the medical model, disability is cast as defective and unnatural, which has historically been used to justify institutionalization, medical interventions such as forced sterilization, and other material violences that are rationalized under the guise of rehabilitation and the elimination of non-normative bodyminds.

Critical of the medical model, disability studies trains a critical lens on notions of rehabilitation, fixing, and cure. Eli Clare, for one, reflects a sentiment about how people respond to his cerebral palsy, stating how, "[People] assume me unnatural, want to make me normal, take for granted the need and desire for cure."[47] Many have pointed out that cures may not always be

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[43] Rachel Adams, "Disability," in *Keywords for Disability Studies*, ed. Rachel Adams, Benjamin Reiss, and David Serlin (New York: NYU Press, 2015).

[44] Recognizing Deaf culture, deafness is not a disability, although through the medical model, it is often understood as a 'deficit' that needs to be fixed. However, I recognize how D/deaf people are impacted by ableism, audism, discrimination, and lack of accessibility. Through solidarity, the D/deaf and disabled communities work together to dismantle systems of oppression that affect both communities.

[45] Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: NYU Press, 1998), 11.

[46] Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: NYU Press, 1998), 11.

[47] Eli Clare, *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, ed. Sarah Jaquette Ray and Jay Sibara (Lincoln, NE: University of Nebraska Press, 2017), 245.

desired, where we can, as Kafer states, "recogniz[e] illnesses and disability as part of what makes us human."[48] Describing being at the margins, Mia Mingus states "I love living out there. There are amazing things and people out there. And it shouldn't be that that's the only place where we can be whole."[49] Rosemarie Garland-Thomson even makes the case for conserving disability, describing "what disabled people-as-they-are contribute to our shared world…. The generative work of disability and people with disabilities through their presence in the world... [that] refuses the dominant understanding of disability as a deficit to be tolerated and protected and seeks to bring forward the benefit disability brings to the human community."[50] In other words, eliminating disability is not necessarily a desirable goal, which unsettles, as Kafer describes, "this belief that we all desire the same futures."[51] Disability studies scholars have highlighted that disabled people may not desire to be fixed, do not need to disavow, rise above, or overcome difference, and moreover find identity, community, pleasure, and activism in being disabled.

The rehabilitation of disabled bodyminds, additionally, can be harmful. In his book *Brilliant Imperfection*, Clare highlights the complexity of rehabilitative rhetorics: "Cure saves lies; cure manipulates lives; cure prioritizes some lives over others; cure makes profits; cure justifies violence; cure promises resolution to body-mind loss."[52] Rehabilitation is accessible to those who have financial means and produces profits for medical and pharmaceutical industries

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[48] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 4.

[49] Mia Mingus, "'Disability Justice' Is Simply Another Term for Love," *Leaving Evidence* (blog), November 3, 2018, https://leavingevidence.wordpress.com/2018/11/03/disability-justice-is-simply-another-term-for-love/.

[50] Rosemarie Garland-Thomson, "The Case for Conserving Disability," *Journal of Bioethical Inquiry* 9, no. 3 (July 18, 2012): 339–55, https://doi.org/10.1007/s11673-012-9380-0, 343.

[51] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 3.

[52] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham London: Duke University Press Books, 2017), xvi.

who promise the normalization of bodyminds. Eunjung Kim identifies, "What is problematic in the drive for medical cure is its narrow, simple focus on the gains and benefits that cure may bring, disregarding its associated harms, risks, and disenabling effects. It also closes off ways to support, in the present, 'untreated' and 'incurable' lives, that is, people who have a disability or an illness, as well as people who refuse or cannot afford treatments."[53] She identifies how the endeavor for a cure can enact harm, stating, "cure carries significant risk of unwanted changes or even death."[54] Rehabilitative rhetorics not only cast those who do not want or cannot access cures in a negative light, but also the very act of curing or fixing can enact its own harm.

While critiquing rehabilitative rhetorics of disability, Clare draws attention to disabled bodyminds, that not only don't always desire a cure, but also might not have ever been 'whole' (or non-disabled) in the first place. Therefore rehabilitation—"the regaining of skills and abilities that have been lost or impaired"[55]—is not possible "because an original nondisabled state of being doesn't exist."[56] He centers his own narrative in how there may never have been a whole, a non-disabled bodymind, to return to, emphasizing,

> First, cure requires damage, locating the harm entirely within individual human body-minds, operating as if each person were their own ecosystem. Second, it grounds itself in

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[53] Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham: Duke University Press Books, 2017), 7.

[54] Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham: Duke University Press Books, 2017), 13.

[55] Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham: Duke University Press Books, 2017), 8.

[56] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham London: Duke University Press Books, 2017), 15.

an original state of being, relying on a belief that what existed before is superior to what exists currently. And finally, it seeks to return what is damaged to that former state.[57]

Along these lines, Kim identifies a similar direction, that "cure keeps its place as a destination at which one can never arrive."[58] Through a critical attention to the nuances of cure and rehabilitation—that may not be desired, may enact harm, and may not even be possible—disability studies provides frameworks for unsettling assumed desires, orientations, and rhetorics around incompleteness. Drawing attention to a 'whole' might not have ever existed, might not be desired, or might be impossible to return to, then, facilitates decentering orienting backwards—a focus on what might have existed before and therefore what could be restored today.

Returning to thinking about 'archives as body' and 'dismembered fonds' through this lens first echoes the critiques of traditional provenance upholding historic inequities. Drake emphasizes the risk of provenance as "a relic of the colonial and imperial era... which reflect[s] the bureaucratic and corporate needs of the Western colonial, capitalist, and imperialist regimes in which archivists have most adhered to the principle."[59] Just as disabled people may not desire a cure, many marginalized communities may not benefit from restoring or maintaining the provenance of a fonds. Kim notes how "cure is always a multifaceted negotiation, often enabling

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[57] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham London: Duke University Press Books, 2017), 15.

[58] Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham: Duke University Press Books, 2017), 9.

[59] Jarrett M. Drake, "RadTech Meets RadArch: Towards A New Principle for Archives and Archival Description," Medium, *On Archivy* (blog), April 6, 2016, https://medium.com/on-archivy/radtech-meets-radarch-towards-a-new-principle-for-archives-and-archival-description-568f133e4325#.rxi38ik03.

and disabling at the same time, and may be accompanied by pain, loss, or death."[60] Putting these critiques in conversation around archival material and historical hierarchies highlights how traditional provenance and working towards restoring or maintaining original order can not only maintain particular perspectives within archival material, but also actively cause harm—to those whose world views records don't reflect.

Second, disability studies critiques of restoring emphasize the impossibility of restoring a fonds because records are lost, moved, or never selected to be in an archives. Some scholars have drawn attention to the impossibility of restoring a complete fonds. Millar, for one, articulates, "The intellectual reality of provenance and the physical reality of the records are not equal. One body of records can derive from many creators, and one creator can leave records in many physical locations. Provenance and the fonds are not the same, nor do they represent a constant, one-to-one relationship."[61] The idea that all records created by one origin should be kept in the same place is "unreasonable, impractical, and unrealistic," because "the fonds implies a wholeness, a completeness, a totality," which no archives will ever have as records are lost, stolen, destroyed, and don't enter an archives for various reasons.[62] Likewise, the records documenting the WCE, created by multiple people and entities, kept or discarded for different reasons, echo these sentiments. Their multiplicity and partialities highlight how multiple people and entities can create records around a single event, an impossible kaleidoscope of materials. As records were created, they were dispersed across different entities—visitors, photographers,

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[60] Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham: Duke University Press Books, 2017), 7.

[61] Laura Millar, "The Death of the Fonds and the Resurrection of Provenance: Archival Context in Space and Time," *Archivaria* 53, no. 0 (January 1, 2002): 51–15.

[62] Laura Millar, "The Death of the Fonds and the Resurrection of Provenance: Archival Context in Space and Time," *Archivaria* 53, no. 0 (January 1, 2002): 6.

exhibitors, architects, etc.—and then continued to move—associated with individuals' personal papers, governing boards, and, eventually, archives.

This framework emphasizes the impossibility of restoring a fonds because it never was whole in the first place. Just as Clare demonstrates that his bodymind was never not disabled, so too can we understand archival materials as always already incomplete. Artificial collections, such as the "World's Columbian Exposition Ephemera Collection" at Harold Washington Library Special Collections, contained maps and other ephemera from the fair, many of which came from different sources and some of which had unknown authors, histories, and provenance. These records illustrate how restoring traditional provenance, or reconstructing a history of a record may not be possible because the fonds were never whole in the first place—individual records were incorporated as part of this collection. Building on critiques of provenance, which can risk maintaining and reifying traditional inequities, and paralleling disability studies critiques, where rehabilitation may not be desired, may cause harm, and may not even be possible, this research emphasizes how traditional provenance is incompatible with many archival realities.

Reorienting Towards a Crip Provenance

If restoring provenance is not possible or not desirable, what might embracing a new disability studies or crip orientation to records look like? Thus far I have meandered through the reality of records I found in researching the WCE—created by different people, processed in different ways, and located in multiple archives. I've shown how provenance in reality is messy, incomplete, rumored, and sometimes unknown, and how, when thinking of archives as bodies, we may come to terms with the inevitability of restoration of a fonds. And, thus far, I have yet to mention disabled people within these records, not because I'm avoiding them, but because they

often weren't often obviously there. I'm sorry to say that I'm not surprised. Given the dominant ways in which disabled people have been documented, I wasn't expecting to find much—if any—explicit documentation of them in a history outside of medical, criminal, and institutional records. Returning to the guiding question of this project—how to tell a history of disability when there is little to no evidence—I create this expansive framework as one possible answer.

This section, building off of the previous sections, aims to reorient provenance, to turn it around, and instead of longing for a former whole, to embrace records' realities—in other words, meeting records where they're at *literally* (dispersed and duplicated in different archives) and *figuratively* (as temporally, spatially, and historically situated yet always already incomplete). In doing so, I not only acknowledge the partial histories of records, but also all of the new contexts and connections of records that may facilitate in retelling history through a different lens. Evoking disability studies scholarship that centers the proximities created through and because of disability—as it is in relation to other disabled people and histories (through activism and intersectional identities), materials (through technology and assistive devices), attitudes (through discrimination), places/spaces (through built environments, accessibility, and place) and power (through the interinformed connections of ableism to other forms of oppression)—a *crip provenance* radically reorients provenance. Instead of focusing strictly on the former (often fictitious) whole fonds, it emphasizes the relations created specifically because records are incomplete, dispersed, unknown, and rearranged. This framework is not about entirely rejecting the provenance of records—valuable information can be obtained through an attention to the history of a record and its context—but by fixating on what *has happened*, we miss *what happens* because fonds are always already fragmented, incomplete, and dispersed.

As I explained above, the medical model of disability simplifies and individualizes disability, which orients disabled bodyminds in a position to be fixed, rehabilitated or cured. Many disability studies scholars have rejected the simplification and individualization of disability and have argued "that disability should be understood as a minority identity, not simply as a 'condition' of lack or loss to be pitied or 'overcome.'"[63] Developed as a response to the medical model, *the social model of disability* addresses the social constructs that inhibit disabled people from having equal access to opportunities and resources that would otherwise help them to "participate fully in society, to live independently, to undertake productive work and to have full control over their own lives."[64] Instead of lying within the disabled body or mind, "the problem of disability is located in inaccessible buildings, discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies."[65] Through this lens, Kafer says, "[t]he problem of disability is solved not through medical intervention or surgical normalization but through social change and political transformation."[66]

By problematizing the individualizing and normalizing qualities as well as the complexity of medical intervention of the medical model alongside the societal and cultural constructions of the social model of disability, Kafer has more recently developed the political/relational model of disability. The political/relational model builds off the social model by shifting away from understanding disability as a purely medical "problem" of the body/mind,

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[63] Robert McRuer, "Critical Investments: AIDS, Christopher Reeve, and Queer/Disability Studies," *Journal of Medical Humanities* 23, no. 3–4 (December 1, 2002): 221–37, https://doi.org/10.1023/A:1016846402426, 223.

[64] Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard Davis, 2 edition (New York: Routledge, 2006), 197–204, 200.

[65] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 6.

[66] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 6.

understanding how social and architectural barriers can alienate non-normative bodies, and also incorporating queer and feminist critiques of identity. Kafer's model, unlike the social model, does not differentiate between impairment and disability. She states that "impairment refers to any physical and mental limitation, while disability signals the social exclusions based on, and the social meanings attributed to, that impairment. People with impairments are disabled by their environments."[67] Kafer refuses the impairment/disability divide so that pain, fatigue, as well as desires for medical intervention can be included in understandings of disability. By applying a feminist and queer perspective of how bodies and identity can shift across time, place, and interactions, her model, as I will describe below, encompasses the relational and political proximities that comprise disability.

Resisting a curative stance towards provenance, and instead embracing a political/relational disability lens, as I will show, highlights all of the new connections of disability to history, which help to build towards a crip provenance. Just as Kafer states, "[t]he problem of disability is solved... through social change and political transformation,"[68] so too do archives require less prescriptive and rehabilitative solutions and instead need expansive, political, and creative approaches. Although I'll apply this lens in more detail throughout the entire dissertation, I will illustrate it through one record from the WCE that shows a trace of disabled people: a magazine which describes an exhibit that may not have ever been created.

While at the Seaver Center for Western History Research—an archives at the Natural History Museum of Los Angeles County—I sifted through "World's Columbian Exposition Collection, 1893," an artificial collection of four linear feet of an assortment of books,

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[67] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 7.

[68] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 6.

magazines, and other publications on the WCE. I came upon the *California's Monthly: World's Fair Magazine*, which describes many potential contributions that California could provide to the WCE, a magazine "Devoted to advancing California's Interests at the Columbian Exposition." After flipping through the pages, I noticed an exhibit proposal: "Pigmies [sic] for the World's Fair." The five paragraph proposal outlines how "Lieut. Mason A. Shufeldt, who has spent nine years in Africa…will… secure a family of Stanley's pigmies [sic] from the equatorial forest," in Zanzibar. It outlines the plans for an expedition "to the dark continent," whereby multiple parties will collaborate to bring to the west coast "a family of twelve or fourteen of the fierce little midgets," to later enslave them in the U.S. As I will discuss in more detail below, the proposal describes the main participants in the expedition which "has been given two years and eight months by the commissioners," to be completed, as well as the multiple cities through which they will pass and other materials they set out to collect, such as "native workmen and crude diamonds" for "a diamond mine in operation at the Fair."

This deeply disturbing record is located in a sea of unknown: I wasn't able to access any provenance notes on the magazine, to locate the author of this featured section, to find subsequent issues, and more importantly, could not find any documentation around if this expedition has occurred or if the exhibit had been built for the WCE. Through a disability studies lens and in building a crip provenance, I will illustrate all of the unknowns about this single record as I describe its details. But while I do so, I will also illustrate all of the ways in which acknowledging all the relationships created by and through disability help me investigate this record. The five short paragraphs of this magazine's featured section illuminate a multiplicity of connections to disability.

First disability studies highlights how disability is in relation to other people. Both the social and the political/relational models of disability emphasize how discrimination shape disabled people's lives. Through "discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies," disabled people's lives are impacted through their interactions with other people, which has been the basis for many anti discrimination laws.[69] And, as Harlan Han identifies, discrimination can therefore impact their "socioeconomic status, family ties, unemployment rates, and related social problems."[70] To the contrary, through community, activism, and cross disability solidarity, interactions with other disabled people can radically impact disabled people's lives in positive ways. Hahn notes that, "For some disabled individuals, including the leadership of the social and political movement of people with disabilities, the effects of this change have been profoundly liberating."[71] Concepts like 'interdependence'—which as Mia Mingus defines, "moves us away from knowing disability only through 'dependence,' which paints disabled bodies as being a burden to others"—highlight how a disabled bodymind does not exist in a vacuum, but is shaped through interactions with other people—through discrimination, through activism, and through community.[72]

When embracing such proximities in working towards a crip provenance, we can add context to this record through thinking about all of the people who are interconnected through archives. Through this lens, I can recognize the subjects of this record, as their minimal

[69] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 6.

[70] Harlan Hahn, "The Political Implications of Disability Definitions and Data:," *Journal of Disability Policy Studies*, July 24, 2016, https://doi.org/10.1177/104420739300400203.

[71] Harlan Hahn, "The Political Implications of Disability Definitions and Data:," *Journal of Disability Policy Studies*, July 24, 2016, https://doi.org/10.1177/104420739300400203, 49.

[72] Mia Mingus, "Interdependency (Excerpts from Several Talks)," *Leaving Evidence* (blog), January 22, 2010, https://leavingevidence.wordpress.com/2010/01/22/interdependency-exerpts-from-several-talks/.

description could produce what Tonia Sutherland describes as "places of oblivion," that "silences the voices and histories of marginalized peoples and communities."[73] I also can recognize the multiple people involved in the construction of the exhibition proposal: Lieutenant Shufeldt, who was proposed to lead the expedition; Tippoo Tib [sic], a local guide recruited to "obtain the pigmies [sic] by purchase;" California WCE board members and commissioners, who worked to organize and fund exhibitions and exhibits; the people of Zanzibar, Congo, Sierra Leone, Libera, and other south and central African areas targeted through such an exhibition. Furthermore, I consider not only all of the people, organizations, governing boards, etc. that were involved in the production of records, but also all of the people who have interacted with them since: I've described some interactions, conversations, and emails that I've had with archivists throughout this research, and also think about the ways in which archivists are active participants in shaping historical narratives. The decision making around how records are processed impacts how I am able to find, interpret, and experience records. I'm also drawn to think not only about my experiences interacting with archivists, but also my experiences looking for disabled people in history—the feelings of longing, excitement, sadness, and loss that occur when I search for disabled people in archives. And also how my experiences in archives are shaped by my experiences in disabled communities—how activism, advocacy, and community have all shaped my identity and my understandings of disability, which inform how I am able to perceive disability in records, how I am forming this theoretical framework, and even how this project began from their rumors. There are many people—myself and my community included—who I consider in proximity to this record as it exists in an archives today.

[73] Tonia Sutherland, "Archival Amnesty: In Search of Black American Transitional and Restorative Justice | Journal of Critical Library and Information Studies," *Journal of Critical Library and Information Studies* 1, no. 2 (June 2017), https://journals.litwinbooks.com//index.php/jclis/article/view/42, 19, 17.

Second, disability studies emphasizes systems of power, how disability is political because it is historically and spatially contingent as well as bound up and deeply intertwined with other systems and histories of oppression. Disability Justice activist Patty Berne notes, "[w]e cannot comprehend ableism without grasping its interrelations with heteropatriarchy, white supremacy, colonialism and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of a subjugated 'other' from whom profits and status are extracted."[74] And those historical politics become embodied in contemporary rhetorics, such as language. Paul Banahene Adjei describes "the myriad of ways in which ableist languages justify classifications of some people as less than human, re-enacting pervasive colonial racist ideologies and practices."[75] Such ways of devaluing bodyminds become embodied within language, classificatory systems, and systems of documentation that are maintained, changed, and experienced today.

Through this lens, I am drawn to think about the interlocking systems that framed the Pygmy people as "fierce little midgets"—just a trace of them in this record evoke how racism and ableism are bound up in colonial projects such as this, to produce hierarchies of living beings as well as events, such as the WCE, that demonstrated white western supremacy and the production of knowledge. Moreover, this lens allows me to think not only about the historical systems at work in producing the documentation around the WCE, but also the archival systems that organize, describe, and therefore replicate or alter them. Having navigated multiple archival systems such as finding aids, online databases, and catalogs, I can reflect on how they're

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[74] Patty Berne, "Disability Justice – a Working Draft by Patty Berne | Sins Invalid," June 10, 2015, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne.

[75] Paul Banahene Adjei, "The (Em)Bodiment of Blackness in a Visceral Anti-Black Racism and Ableism Context," *Race Ethnicity and Education* 21, no. 3 (May 4, 2018): 275–87, https://doi.org/10.1080/13613324.2016.1248821.

organized. As stated earlier, while some archives maintain fonds' previous organization, others have established 'artificial collections' where they gather records and organize them based on specific topics. And some records were kept in original order, which could provide me context, but others were out of order, or had an unknown order in an artificial collection, each of which has varying levels of description on the contents of records. The fonds description of "Publications from the 1893 Chicago World's Fair, the World's Columbian Exposition," did little to draw attention to the problematic nature of the content of a magazine, further obscuring it. Through this lens, I'm able to draw attention to such systems and how they are reflected or obscured through language, both in the record itself as well as in the finding aid.

Third, in developing a crip provenance, I'm drawn to think about how disability is not only political through systems but also through materials. A political/relational approach to disability emphasizes "how bodies move, meet, co mingle, and mesh with technology, architecture, and objects,"[76] and how disability is connected to power and politics through materiality. Kafer emphasizes that "our bodies are not separate from our political practices; neither assistive technologies nor our uses of them are ahistorical or apolitical."[77] She highlights Steven Kurzman's tracing of his prosthetic leg's components to materials that are based in military technology, have a history in post–Cold War production, and can only be accessed through a job which offers health insurance to reduce cost.[78] The materials in everyday life, including within an archives and records, can be traced to power and politics.

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[76] Jasbir Puar, *Terrorist Assemblages: Homonationalism in Queer Times* (Durham: Duke University Press Books, 2007), 209.

[77] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 120.

[78] Steven L. Kurzman, "Presence and Prosthesis: A Response to Nelson and Wright," *Cultural Anthropology* 16, no. 3 (2001): 374–87.

Therefore in expanding a crip provenance to include materiality as providing context, I can also consider the materials surrounding the exhibition proposal as well as the WCE. In addition to the primary goal of the expedition, the magazine section also outlines how "From Zanzibar, Lieut. Shufeldt will proceed to Natal, Port Elizabeth, Cape Town, and the Transvaal. The Cape colonies will be requested to exhibit a diamond mine in operation at the Fair. Chicago will furnish the mine and the colonies will be asked to supply native workmen and crude diamonds." Situated with the WCE, which was central to exhibiting materials, scientific technologies, and architectural feats that displayed progress, the proposed expedition simultaneously emphasizes a history of colonization and labor exploitation through proposing an additional exhibit of a diamond mine. Also, considering the politics of materials also allows for me to foreground the magazine itself and the materials used to preserve paper, prevent mold, and the various preservation practices within archives.

Lastly, disability studies has drawn attention to the politics of space and place, how physical environments shape disabled people's lives. The social model, central to the disability rights movement, shifts responsibility away from disabled minds and bodies and on to the ways in which social and architectural barriers can be disabling. Stairs, for example, "create a functional 'impairment' for wheelchair users that ramps do not."[79] Harlan Hahn identifies, "Once we begin to realize that disability is in the environment then in order for us to have equal rights, we don't have to change but the environment has to change."[80] Building towards a crip

[79] Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, 1st edition (New York: Columbia University Press, 1996), 7.

[80] Harlan Hahn qtd in Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: NYU Press, 2006), 52.

provenance, like the social and political/relational models of disability, encompasses the ways in which spaces impact disabled peoples' lives.

The California World's Fair Magazine connects multiple spaces and places that expand context of provenance. The many geographies outlined in the small featured section all are connected through a network of colonial endeavors that can give context to the record. From London to Zanzibar, “to Monrovia, Liberia Free State, and to Sierra Leone, in quest for more exhibits,” to Chicago where these people, materials, and politics confer, each of these geographies hold temporal and spatial specificities and histories. Jasbir Puar, focusing on the spatial specificities of US imperialism and Israel’s “project of rehabilitation” of Palestine, teases out a history of disablement. Disability, she shows, is deeply interwoven in histories of exploitation, war, infrastructure and imperialism, where “Maiming thus functions… as the end goal in the dual production of permanent disability via the infliction of harm and the attrition of the life support systems that might allow populations to heal from this harm.”[81] With this in mind, we can contextualize this record within a global, imperial project that was to be showcased at the WCE, through which such projects disable people, bring disease, and colonize. Thus, through an attention to the spatial relations of disability, this record is also in proximity to the disabling effects of colonial expeditions, diamond mining, and the display of “native workmen and crude diamonds” at the WCE. To consider spatial relations of disability brings in the geographical specificity of colonial endeavors, the disabling impacts of a transnational expedition, and the spatial construction of exhibits at the WCE.

Separately, my experiences as a Disabled person in archival spaces has become part of the context of this records—maneuvering the halls of the Natural History Museum of Los

[81] Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham London: Duke University Press Books, 2017), 143.

Angeles County to locate the archival space in the basement, sitting in the archives reading room, using a lightbox to view slides, navigating the digital spaces such as websites, database and digital finding aids, not to mention all of the other archival spaces I visited as part of this research. To consider space is also to acknowledge how disabled people experience it—how archives produce context through the spaces in which materials are kept, processed, and organized *and* how multiple archives are connected through my research on this topic. This framework connects all of the archival spaces that contain records on the WCE, as records are dispersed and understood differently in different spaces and times. And through this lens multiple spaces, histories, and materials are illuminated in this one record. All of these facets help me tell a new history of disability from just a trace of disabled people in history.

Through this short example of an exhibition that I can't find evidence of ever being made, of a record with very little context, of a trace of disabled people in history, I can consider a constellation of new connections that allow me to grapple with these traces and absences of disability in history. When considering the records that document the history of the Field and WCE, a crip provenance, as I've shown, can facilitate grappling with the partialities by not only focusing on what is in the records and what we can figure out about the history of these records, but also by meeting them where they are at today. The records created because of the World's Columbian Exposition, created by different people, organizations, governing bodies, and individuals—or never created at all—document a piece of the history of the Field Museum. Yet, as I've described, not only is reconstructing a provenance impossible, but new connections can be made to illuminate a new story with disability at the center. The provenance of these records provides us with some context—how records have been moved, organized, accessioned, etc.—however, recreating the provenance is not only impossible, but also it may be a misorientation to

these records, which does them a disservice, especially when trying to tell a new history, that may lay outside of traditional forms of evidence.

Crip provenance—a disability-centered framework that resists the desire to restore and instead meets records where they are at in order to acknowledge all of the new connections and relations that are created because records are always already dispersed, duplicated, and partial—builds off of concepts like societal provenance, which draw attention to how "people play a role in *causing* the record we see today to *exist*."[82] Like societal provenance, crip provenance takes into account the societal dimensions that are infused into "creator(s), functions, and organizational links and structures," as well as the people and mediums that shape records creation.[83] However, societal provenance still maintains undertones of restoring or attempting to depict a 'complete' historical picture. Through a specific attention to the relationality of disability *and* through resisting rehabilitative orientations to fonds, a crip provenance draws more attention to absences, messiness, and the impossibility of knowing a complete disability history. It not only considers the connecting histories of records and the people, materials, languages, and systems—expanding outward from a single record or fonds to consider influential, interwoven, and parallel factors—that informed its existence, but also faces forwards—drawing attention to the new connections that are created because records are moved, reorganized, processed, and experienced at different moments. Paying attention to the

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[82] Tom Nesmith, "What's History Got to Do With It?: Reconsidering the Place of Historical Knowledge in Archival Work," *Archivaria* 57, no. 0 (January 1, 2004): 1–27; Tom Nesmith, "The Concept of Societal Provenance and Records of Nineteenth-Century Aboriginal–European Relations in Western Canada: Implications for Archival Theory and Practice," *Archival Science* 6, no. 3 (December 1, 2006): 351–60, https://doi.org/10.1007/s10502-007-9043-9.

[83] Tom Nesmith, "What's History Got to Do With It?: Reconsidering the Place of Historical Knowledge in Archival Work," *Archivaria* 57, no. 0 (January 1, 2004): 1–27; Tom Nesmith, "The Concept of Societal Provenance and Records of Nineteenth-Century Aboriginal–European Relations in Western Canada: Implications for Archival Theory and Practice," *Archival Science* 6, no. 3 (December 1, 2006): 351–60, https://doi.org/10.1007/s10502-007-9043-9.

proximities of disability, I reorient provenance and resist the normative forms of lineage, hierarchy, ownership that traditional provenance offers. However, I choose to continue to use the word ‘provenance’ to describe this orientation to archival context, instead of ‘proximity’, as a way to build on societal provenance and continue to speak to the archival communities where this concept can be applied.

As this dissertation will show in more detail, a crip provenance (Figure 1) emphasizes *people*—not only creators, subjects, and archivists but also the people who experience, interpret, and are impacted by records across time—*systems*—not only that created the record but created and influenced the creation of other records that influenced other systems, legislation, archival processes, etc.—*materials*—not just those which are present in the record itself, but the parallel histories and practices that make discussing disability and ableism possible when they are not apparent—and *spaces*—the histories of and affective ways in which accessibility is interwoven into all of the previous aspects. By placing emphasis on all of the people, places, materials and language in relation to the history of the Field Museum—proximities that occur specifically because records are dispersed, duplicated, and experienced and specifically because of disability and archives—these records not only expose the trouble with traditional provenance, but more so, illuminate the new connections that can be made through acknowledging this reality.

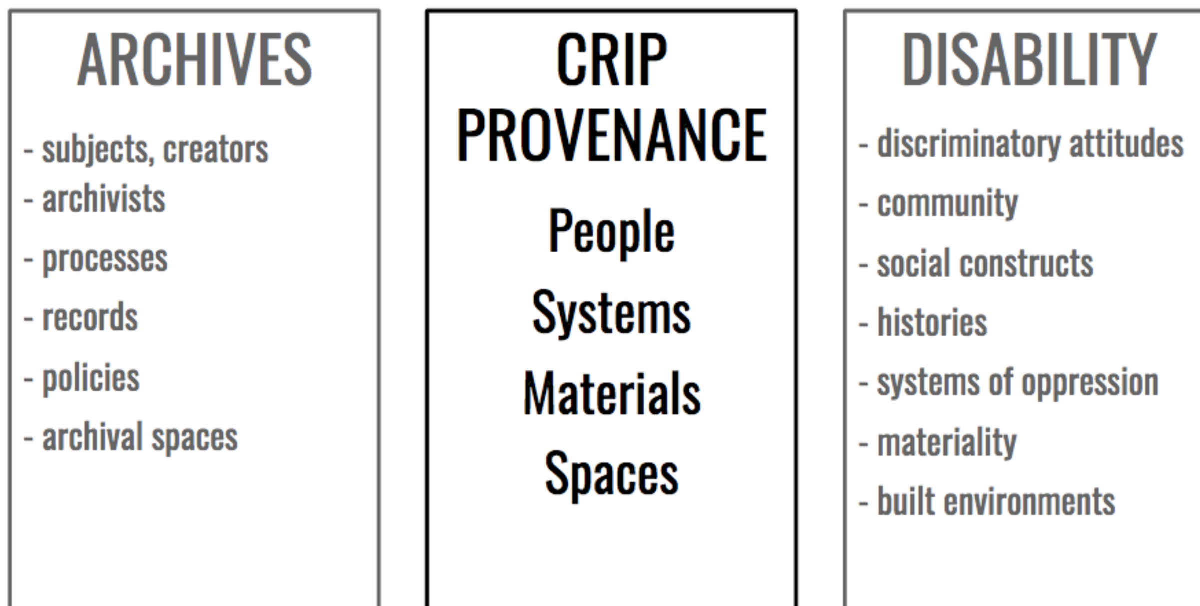

Figure 1: Archival and disability relationships that form the four facets of a crip provenance. *The four facets of a crip provenance are listed as: people, systems, materials, and spaces, which draw on relationships formed by archives and disability. The relationships formed through archives are listed as: subjects, creators, archivists, processes, records, policies, and archival spaces. And the relationships formed through disability are listed as: discriminatory attitudes, community, social constructs, histories, systems of oppression, materiality, and built environments.*

Each of these facets that I have described facilitate thinking expansively of all of the proximal relations that we can consider that may help us grapple with partial histories. And in building this expansive framework for thinking about disability in history, I set the stage for the rest of the dissertation. Each chapter takes a proximity that I have described—people, systems, materials, and spaces—and puts it into action. Kafer tells us "A political/relational model of disability... makes room for more activist responses, seeing 'disability' as a potential site for collective reimagining."[84] Likewise, through a crip provenance lens, we can address inequities, misrepresentations, and silences around disability and look expansively at how records in proximity to one another can tell a new story about disability and colonialism.

[84] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 9.

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Chapter Two: Research Design
Methodology & Methods

Introduction

This chapter covers the overarching methodology of theory construction for this dissertation. I will first describe this methodology and how theory and practice are intertwined within archival studies and disability studies. Then, under this methodology, I will discuss the data collection methods for this dissertation. First, through semi-structured interviews with disabled scholars, activists, artists, and community members, I turn to how living disabled people experience archival materials and witness disability in history. I will illustrate my study design, participant selection, as well as my confidentiality and consent processes. Then I will describe my second data collection method: historical/archival methods. Within this I will outline the selection of my sites and materials. Following the description of these two methods, I will discuss my processes of data analysis as well as the limitations of this study. These two techniques of data collection have been intentionally selected, as a theoretical sampling, to think through the complexities of misrepresentation and erasure; one specifically looks at the effect, affects, and needs of the disabled community and the other builds theories around contending with such impacts in archival materials around the history of the Field Museum.

Methodology

This dissertation is situated within the methodology of theory construction—I build theory from both close readings of records, historical documents, as well as empirical data gathered through semi-structured interviews and use critical theory as a foundation for understanding and deconstructing layers of power. The use of critical theory, such as disability

studies and feminist theory, allows me to frame and interpret power embedded in archival and museum systems and thus to construct theories around these phenomena, in attempts to "expose the forces that prevent individuals and groups from shaping the decisions that crucially affect their lives."[1] Kincheloe and McLaren note that "critical social theory is concerned in particular with issues of power and justice and the ways that the economy, matters of race, class, and gender, ideologies, discourses, education, religion and other social institutions, and cultural dynamic interact to construct a social system."[2] Williamson points to how "there are strong links between critical theory, postmodernism and postcolonialism,"[3] which facilitate understanding structures of power in information systems. Within information studies, the broader field in which archival studies is situated, Williamson describes how theory "informs the research process and helps direct it," noting that "When researchers set out to develop theory, they will usually search for other theories and research to inform the process... [T]heory helps to encourage cumulative, rather than a fragmented approach."[4] Research within information studies can lead to the "discovery or creation of knowledge, or theory building" and analyzing systems can facilitate theory building "where a theory can be illustrated by a system,"[5] such as archive, museum, and other knowledge organization systems. Moreover, as Lynham outlines, a critical

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[1] Joe L Kincheloe and Peter McLaren, "Rethinking Critical Theory and Qualitative Research," in *The Landscape of Qualitative Research: Theories and Issues*, ed. Norman K. Denzin and Yvonna S. Lincoln, 2nd edition (Thousand Oaks, Calif: SAGE Publications, Inc, 2003), 433–88, 437.

[2] Joe L Kincheloe and Peter McLaren, "Rethinking Critical Theory and Qualitative Research," in *The Landscape of Qualitative Research: Theories and Issues*, ed. Norman K. Denzin and Yvonna S. Lincoln, 2nd edition (Thousand Oaks, Calif: SAGE Publications, Inc, 2003), 433–88, 436-7.

[3] Kirsty Williamson, "Research Concepts," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 3–23, 15.

[4] Kirsty Williamson, *Research Methods for Students, Academics and Professionals: Information Management and Systems* (Elsevier, 2002), 59.

[5] Kirsty Williamson, *Research Methods for Students, Academics and Professionals: Information Management and Systems* (Elsevier, 2002).

view of theory building can be aimed to "enlighten and emancipate through the process of critique and identifying potential."[6] Thus identifying and theorizing how power operates can be aimed towards addressing and dismantling how legacy systems of power and authority function.

The process of using critical theory and developing theory is inherently interpretive and iterative. Although, as Williamson points out, interpretivists are critiqued by critical theorists as being too subjective—focusing too closely on microlevel and short term issues, and therefore potentially ignoring larger-scale issues and long-term solutions. However, Cecez-Kecmanovic specifies that, "critical IS researchers go further to expose inherent conflicts and contradictions, hidden structures and mechanisms accountable for these influences."[7] Therefore, interpretivist approaches can focus on the details and specifics of circumstances unique to individuals as well as broader phenomena and long-term solutions. Williamson states that "Researchers who are interpretivists favour naturalistic inquiry (where field work usually takes place in the 'natural setting') are concerned with 'meaning'. They believe that the social world is interpreted or constructed by people and is therefore different from the world of nature."[8] An interpretivist approach also centers how researchers come with their own positionalities and translate their findings in ways unique to them.

Likewise, Meekosha and Shuttleworth remark about the reflexivity of working with critical disability studies:

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[6] Susan A. Lynham, "The General Method of Theory-Building Research in Applied Disciplines," *Advances in Developing Human Resources* 4, no. 3 (August 1, 2002): 221–41, https://doi.org/10.1177/1523422302043002, 226.

[7] Eileen Moore Trauth and Dubravka Cecez-Kecmanovic, eds., "Doing Critical IS Research: The Question of Methodology," in *Qualitative Research in IS: Issues and Trends*, 1 edition (Hershey, PA: Idea Group Publishing, 2001), 142–63, 143.

[8] Kirsty Williamson, *Research Methods for Students, Academics and Professionals: Information Management and Systems* (Elsevier, 2002), 30.

> "Since critical social theory recognises the inherent historicity of society - that it is susceptible to change - the concepts critical social theory employs are always an investment in bringing about social change. However, critical theory also recognises its own situatedness within a particular historical moment. Thus, it is obliged to maintain a critical self-reflexivity toward its own theories and praxis. It is not as if an unmasking of the oppressive dynamics within a particular society or concerning a particular social group can be theorised and acted upon definitively. The ever changing social relations, cultural meanings and thus self-understandings necessitate a hyper-vigilance towards the possibility of changed terms of engagement."[9]

These processes "tend to be iterative, with various elements in the research being interwoven: the development of one influences decisions about the others."[10] Embracing the iterative nature allows this project to shape and be shaped by the use and building of theory, as well as through the collection of data. Specifically by focusing on how power is entwined with archival systems, that have historically affected disabled people and perceptions of them, this project looks at the broad application of disability studies to archival studies through the amplification of voices of disabled writers, scholars, and artists, to theorize how those voices, and many like them, have been affected disproportionately by the violence of archives throughout history. This project, aimed at building theory around archival representation of disability, will draw heavily from critical disability studies as well as theorize new concepts by specifically thinking about

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[9] Helen Meekosha and Russell Shuttleworth, "What's so 'Critical' about Critical Disability Studies?," *Australian Journal of Human Rights* 15, no. 1 (November 1, 2009): 47–75, 53, https://doi.org/10.1080/1323238X.2009.11910861.

[10] Kirsty Williamson, "Research Concepts," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 3–23, 14.

disability's proximities within archives in an iterative and interwoven fashion. As I will show below, theory building has been used outside of archival studies to theorize the power embedded in archives and has also been used as a methodology within archival studies to radicalize archival theory and practice.

Historically, scholars such as Foucault and Derrida have been invested in theorizing how power is embedded in archives and archival processes, which also overlaps with how disability is theorized and understood. Notably, Derrida coined the term "archive fever" which centers feverish—sick—archival manifestations of power, "not only with archives of evil, but with 'le mal radical', with evil itself."[11] 'The Archive' as understood by Derrida, is the materialization of layers of power and, ultimately, the death drive. To unpack this, he centers a critique of Freud's patriarchal logics and "civilizing progress of reason,"[12] claiming that psychoanalysis formalizes Freud's archive as "it repeats the very thing it resists or which it makes its object."[13] Foucault theorizes about the accumulation of knowledge and the development of discourses.[14] He states:

> "The idea of accumulating everything, of establishing a sort of general archive, the will to enclose in one place all times, all epochs, all forms, all tastes, the idea of constituting a place of all times that is itself outside of time and inaccessible to its ravages, the project

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[11] Carolyn Steedman, *Dust: The Archive and Cultural History* (New Brunswick, N.J: Rutgers University Press, 2002), 8.

[12] Jacques Derrida and Eric Prenowitz, "Archive Fever: A Freudian Impression," *Diacritics* 25, no. 2 (1995): 9–63, https://doi.org/10.2307/465144, 60.

[13] Jacques Derrida and Eric Prenowitz, "Archive Fever: A Freudian Impression," *Diacritics* 25, no. 2 (1995): 9–63, https://doi.org/10.2307/465144, 91.

[14] Michel Foucault, *The Archaeology of Knowledge: And the Discourse on Language* (New York: Vintage, 1982).

> of organizing in this way a sort of perpetual and indefinite accumulation of time in an immobile place, this whole idea belongs to our modernity."[15]

Frequently engaging with the historical medicalization and categorization of sick and disabled bodyminds, Foucault theorizes classificatory specification as a "system according to which the different 'kinds of madness' are divided, contracted, related, regrouped, classified, derived from one another as objects of psychiatric discourse."[16] Such grids of organization, specifically around sickness and disability, are deployed within archival projects of defining and containing disability. The delineation of madness or of pain functions not only to explore the history of the medical profession and its organization of knowledge (such as with *The Birth of the Clinic*[17]and *Madness and Civilization*[18]) but also more loosely, to draw on the affective nature of archives and memory: In the Preface to the 1961 edition of *The History of Madness*, Foucault states "May [friends] pardon me for making such demands on them and their happiness, they who were so close to a work that spoke only of distant sufferings, and the slightly dusty archives of pain."[19] By taking into account the ways in which people, communities, and history are impacted by archives, theory construction has served to excavate the ways in which institutional power ('the archive') operates in archives and records (an archives).[20]

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[15] Michel Foucault and Jay Miskowiec, "Of Other Spaces," *Diacritics* 16, no. 1 (1986): 22–27, https://doi.org/10.2307/464648.

[16] Michel Foucault, *The Archaeology of Knowledge: And the Discourse on Language* (Vintage, 1982), 42.

[17] Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Vintage, 1994).

[18] Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason*, 1 edition (Vintage, 1988), x.

[19] Michel Foucault, History of Madness (Routledge, 2013), xxxvi.

[20] M. L. Caswell, "'The Archive' Is Not an Archives: On Acknowledging the Intellectual Contributions of Archival Studies," August 4, 2016, https://escholarship.org/uc/item/7bn4v1fk.

With deep ties of theory to practice, archival studies has aimed to provide both theoretical and practical techniques for addressing the history of power and authority that inevitably lies within archives. Joan M. Schwartz and Terry Cook convincingly state that "When power is denied, overlooked, or unchallenged, it is misleading at best and dangerous at worst. Power, once recognized, becomes power that can be questioned, made accountable, and opened to transparent dialogue and enriched understanding."[21] Anne Gilliland and Sue McKemmish describe "discursive writings on the nature of archival theory and how it can or cannot be distinguished from praxis."[22] Theory building has functioned to produce models of practice[23] and, as Preben Mortensen tells us, "becomes an examination of a practice or of practices, aimed at articulating those general principles, ideas, or theories that give these practices their coherence – or perhaps render them incoherent."[24]

Gilliland and McKemmish justify within archival studies that "Theory-building, as a research method, is a means by which the logic that is used to build the theory is made explicit and accessible to the user of the resulting theory."[25] They note how "Whereas 15 years ago,

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[21] Schwartz, Joan M., and Terry Cook. "Archives, Records, and Power: The Making of Modern Memory." *Archival Science* 2, no. 1–2 (March 1, 2002): 1–19. https://doi.org/10.1007/BF02435628, 2.

[22] Anne Gilliland and Sue Mckemmish, "Building an Infrastructure for Archival Research," *Archival Science* 4, no. 3–4 (December 1, 2004): 149–97, https://doi.org/10.1007/s10502-006-6742-6, 154.

[23] For example the records continuum model, Sue McKemmish, "Placing Records Continuum Theory and Practice," *Archival Science* 1, no. 4 (n.d.): 333–59, https://doi.org/10.1007/BF02438901; models for the development and use of LGBTQ archives, Angela DiVeglia, "Accessibility, Accountability, and Activism: Models for LGBT Archives," in *Make Your Own History: Documenting Feminist and Queer Activism in the 21st Century*, ed. Kelly Wooten and Lyz Bly (Los Angeles, CA: Litwin Books, LLC, 2012), 69–104.; and other models of practice, Lawrence Dowler, "The Role of Use in Defining Archival Practice and Principles: A Research Agenda for the Availability and Use of Records," *The American Archivist* 51, no. 1–2 (January 1, 1988): 74–86, https://doi.org/10.17723/aarc.51.1-2.32305140q0677510.

[24] Preben Mortensen, "The Place of Theory in Archival Practice," *Archivaria* 47, no. 0 (February 16, 1999): 20.

[25] Anne Gilliland and Sue Mckemmish, "Building an Infrastructure for Archival Research," *Archival Science* 4, no. 3–4 (December 1, 2004): 149–97, https://doi.org/10.1007/s10502-006-6742-6, 155.

archival research predominantly used historical, survey and case study methods, more recently we can identify the use of… theory-building, and model building, to name some of the methods that have been adopted, adapted, and applied to investigate archival research questions."[26] Moreover, they note that:

> "The broader intellectual context of the differing approaches to research described above encompasses modern and postmodern philosophical, anthropological, sociological, and historiographical thinking, including explorations of the nature of theory itself. This is clearly illustrated in the different understandings and interpretations of the record and the archive that underpin archival research influenced by the different paradigms."[27]

In other words, theory helps one interpret and reinterpret phenomena as well as further build theory out of data. Theory has an important place within archival studies, as Mortensen, tracing different arguments for and against theory within archival studies, states, "An important goal of archival theory is… to clarify the nature of archives and to determine what flows from the nature of archives."[28] He continues, urging, "We must accept something less than pure objectivity. In most disciplines, including the "hard" sciences, practitioners have had to come to terms with this contextual and historical nature of human endeavours, or, to use an expression from current literary theory and philosophy, with the contingent basis for our practices and discourses."[29]

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[26] Anne Gilliland and Sue Mckemmish, "Building an Infrastructure for Archival Research," *Archival Science* 4, no. 3–4 (December 1, 2004): 149–97, https://doi.org/10.1007/s10502-006-6742-6, 174.

[27] Anne Gilliland and Sue Mckemmish, "Building an Infrastructure for Archival Research," *Archival Science* 4, no. 3–4 (December 1, 2004): 149–97, https://doi.org/10.1007/s10502-006-6742-6, 168.

[28] Preben Mortensen, "The Place of Theory in Archival Practice," *Archivaria* 47, no. 0 (February 16, 1999): 2.

[29] Preben Mortensen, "The Place of Theory in Archival Practice," *Archivaria* 47, no. 0 (February 16, 1999): 17.

Considering how theory building helps explain broader phenomena as well as is connected to practice and the embodied ways in which people are affected by archival power, theory—along with the semi-structured interviews and historical methods I will describe below—work in tandem to critically analyze how stories are told. Mortensen tells us that "Historical examination should not be seen as separate from theoretical enquiries… History should be approached not just out of antiquarian interest, but because it can shed light on contemporary concerns. Since archives are historical products, and we are part of that history, bringing that history to awareness can provide insights that make us better able to cope with contemporary concerns."[30] Theory building, then, not only conceptualizes modes of power and draws on practice, but also compliments the critical theory of disability studies and archival theory that serve as a theoretical foundation for this dissertation. Through this project, I hope to do what disability studies, feminist discourse, and archival theory have done throughout each discourse's development: build theory around practice and radicalize traditional approaches to understanding normativized constructs.

Methods for Data Collection

To collect data for theory construction, I will use two primary qualitative methods: semi-structured interviews and historical methods—primarily through records—which work in tandem for the analysis spanning the last century: the historical representation or erasure of disabled people within records and also such representations' contemporary impact on the disabled community. Although this research focuses on natural history museums as a primary case study, it also considers the power of archives and archival representation broadly. As I will describe

[30] Preben Mortensen, "The Place of Theory in Archival Practice," *Archivaria* 47, no. 0 (February 16, 1999): 21.

below, first, data was collected through semi-structured interviews with 10 disabled activists, scholars, artists, and students who have used any archives, not necessarily related to the history of the Field Museum. By beginning this dissertation with empirical research with the disabled community, I first tease out the complexities of the representation of disability in history, how it is often erased or obscured within records, and its effects and affects on the disabled community. This data forms Chapter Three and Chapter Six of the dissertation, demonstrating a need for critical reflection on how disabled people experience records at multiple archives. Then, in grappling with the ways in which disability is misrepresented or absent in records, the two middle chapters, Chapter Four and Chapter Five, use historical methods to closely look at records from the history of the Field Museum of Natural History to theorize what archival interventions may be necessary to reintroduce disability and complicate these histories. By centering the ways in which disability has implicitly or explicitly played a part in the development of this natural history museum and surrounding discourses, the dissertation focused on making a multiplicity of connections between disability and natural history. Patton defines a theoretical sampling, as “incidents, slices of life, time periods, or people on the basis of their potential manifestation or representation of important theoretical constructs.”[31] The two methods are not explicitly linked, however their relationship was established to both think about how archives are experienced as well as the contents of records. These two techniques of data collection have been intentionally selected, as a theoretical sampling, to think through the complexities of misrepresentation and erasure; one specifically looks at the effect, affects, and needs of the disabled community and the other builds theories around contending with such impacts.

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[31]Michael Quinn Patton, *Qualitative Research & Evaluation Methods*, 3rd edition (Thousand Oaks, Calif: SAGE Publications, Inc, 2002), 238.

Semi-Structured Interviews

In the field of information studies, methods such as interviews have been used to explore in-depth people's behaviors and beliefs and gather and assess qualitative data.[32] As Glitz notes, "Qualitative research employs methods that are concerned with words and observations rather than numbers."[33] Performing a qualitative study for this project makes the most sense as I open-endedly explore the broad impacts of archives on the disabled community. This study does not seek to provide positivistic solutions nor assume causality, but instead aims to explore, in depth, qualitative and affective phenomena by collecting data from community members. In this section, I will first show how interviews have been used in information studies to address a wide array of qualitative questions. Then, I will show how these techniques have been used in archival studies to address the impact archives have on historically marginalized groups. Finally, I will address how disability has previously been misrepresented or erased in records, demonstrating a need to investigate the impacts on the disabled community.

Semi-structured interviews have often been a primary technique in gathering data from communities to allow them to express themselves around a given topic. Conducting interviews is one technique that has deep roots in information studies, as it has been deployed to assess users of information systems. With its roots in library and information systems, the field of information studies (IS) has been concerned with the qualitative ways in which people use and experience systems. Working primarily with libraries, Don Fallis asserts that the social aspect of

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[32] Alma Gottlieb, "Ethnography: Theory and Methods," in *A Handbook for Social Science Field Research: Essays & Bibliographic Sources on Research Design and Methods*, by Ellen Perecman and Sara Curran (2455 Teller Road, Thousand Oaks California 91320 United States of America: SAGE Publications, Inc., 2006), 46–84, https://doi.org/10.4135/9781412983211.n3.

[33] B Glitz, "The Focus Group Technique in Library Research: An Introduction.," *Bulletin of the Medical Library Association* 85, no. 4 (October 1997): 385.

life is a critical component of how people learn—knowledge does not live in a single individual nor does everyone experience knowledge seeking in the same ways.[34] Blaise Cronin clearly illustrates "the sociological turn in information science" and demonstrates how the field "routinely interacts with and draws liberally upon other subject fields for intellectual enlightenment,"[35] such as social science methods. Broadly, the field of IS has prioritized not only quantitative but also qualitative methods. For example, drawing on social science and qualitative research literature, many IS scholars, such as Wildermuth[36] and Bow,[37] have utilized qualitative methods to address user concerns, and Sergio Sayago David Sloan, and Josep Blat advocate for the use of such methods in many areas of human computer interaction (HCI) and information systems,[38] while Constance Mellon utilizes anthropological and sociological techniques to investigate aspects of libraries and librarianship.[39] Although these projects address topics vastly different from that of this dissertation, they demonstrate the depth and breadth of which qualitative methods have been used to address the interactions between and impacts of information systems and people.

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[34] Fallis, Don. "Social Epistemology and Information Science." *Annual Review of Information Science and Technology* 40, no. 1 (January 1, 2006): 475–519. https://doi.org/10.1002/aris.1440400119.

[35] Blaise Cronin, "The Sociological Turn in Information Science," *Journal of Information Science* 34, no. 4 (August 1, 2008): 465–75, https://doi.org/10.1177/0165551508088944, 466.

[36] Barbara M. Wildermuth, *Applications of Social Research Methods to Questions in Information and Library Science* (Westport, Conn: Libraries Unlimited, 2009).

[37] A. Bow, "Ethnographic Techniques," in *Research Methods for Students, Academics and Professionals: Information Management and Systems*, ed. Kirsty Williamson (Elsevier, 2002), 177–93.

[38] Sergio Sayago, David Sloan, and Josep Blat, "Everyday Use of Computer-Mediated Communication Tools and Its Evolution over Time: An Ethnographical Study with Older People," *Interacting with Computers* 23, no. 5 (2011): 543–554.

[39] Constance Mellon, *Naturalistic Inquiry for Library Science: Methods and Applications for Research, Evaluation, and Teaching* (New York: Praeger, 1990).

Interviews have served as a meaningful data collection method in archival studies as a means to build theory and derive key concepts that are valuable to the communities which they serve. Similar to the aforementioned literature in information studies, interview techniques have been used in archival studies not only to think about usability, but also about the affective qualities of archives and the materials they contain, particularly with groups historically marginalized by such systems. Michelle Caswell, Marika Cifor, and Mario H. Ramirez, using focus group interviews, meaningfully look at the impact that mainstream archives have on communities of marginalized identities. Through the semi-structured interview technique, they have revealed the ways in which many marginalized identities are *affectively* impacted by under- or mis-representation in mainstream archives. They describe this erasure of identity in mainstream archives using the concept of "symbolic annihilation," where members of underrepresented groups feel essentially erased in history through the ways in which they are not represented in public records.[40] By interviewing users of community-based archives, specifically communities marginalized by race, ethnicity, sexuality, and gender, Caswell, Alda Allina Migoni, Noah Geraci, and Marika Cifor have built on this concept to explore not only the ways in which symbolic annihilation in mainstream archives has negative impacts on communities, but also how community-based archives—archives created, run by, and representing historically marginalized communities—has drastic positive affective impacts: seeing oneself and one's community represented in history can positively inform a complex feeling of belonging.[41] Using the data collected through semi-structured focus group interviews, Caswell et. al. develop theory

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[40] Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (Spring/Summer 2016): 58.

[41] M. Caswell et al., "'To Be Able to Imagine Otherwise': Community Archives and the Importance of Representation" 38, no. 1 (December 1, 2016): 5–26, https://doi.org/10.1080/23257962.2016.1260445.

out of empirical research which allows them to create a rubric for the complex ways in which community archives combat symbolic annihilation through representational belonging. In summary, these works demonstrate how qualitative and interview methods have been used to explore people's experiences with libraries, archives and other information systems and help build theory out of empirical data.

Informed by this work around affect and archives, two chapters examine disabled people's experiences of representation in records (Chapter Three) and their experiences in archival spaces (Chapter Six). Filling a gap in the archival literature on marginalized identities—which has focused mainly on race, ethnicity, sexuality, and gender—and somewhat paralleling the methods of Caswell et. al. in exploring archival erasure, I examine if and how disabled people feel the same or similar symbolic annihilation as other marginalized identities.

Scholars within the field of disability studies have investigated the history of how disabled people are represented in large institutions both by exploring the scarcity of records (or difficulty in finding them) as well as how disabled people have been historically documented for their deviance from the norm. Rosemarie Garland-Thomson has traced the history of the "freak", a construct that is predominantly located within medical discourse and also within fictitious narratives of monstrosity in the U.S. Her work demonstrates how this harmful representation negatively impacts the ways in which disabled people are socially perceived.[42] Historian Kim Nielsen similarly uses records such as sterilization reports, "advertisements for runaway [disabled] slaves," asylum documentation, and American colony records to trace how concepts of disability—the historic oppression of disabled people—have shaped contemporary legislation,

[42] Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, 1st edition (New York: Columbia University Press, 1996).

attitudes and experiences in the United States.[43] Moreover, these representations also make room for recognizing problematic histories and enacting interventions: Julie Anderson and Lisa O'Sullivan demonstrate how narratives of medical knowledge in the past may also open up opportunities for interpretation in museums. They state, "the ability to capture and communicate the experience of the past will always be limited and influenced by the types of records or materials traces left as sources for the historian…. At the same time those objects can be interpreted in new ways that take account of, but are not overly determined by, contemporary values."[44] Likewise, Chris Bell's use of HIV/AIDS criminalization law and case records not only illuminates the violence on Black disabled and queer bodies, but also makes space for Bell to co-construct and respond to public narratives constructed in an archives. He states in reference to one legal case, "The politics of containment are alive and well as *evidence* in: the Cox and Carriker cases, [and] the questionable laws in Atlanta."[45] Centering such laws and legal cases of HIV/AIDS criminalization, he intersperses personal narratives to reflect, respond to, and complicate such records.

Located at the intersection of the affective impacts of archives of historically marginalized communities and the vast representation of disabled people in records as criminalized, spectacularized, and medicalized, Chapter Three and Chapter Six address the ways in which disabled people experience archival materials. These chapters build theory through drawing on the empirical data around how disabled people feel about their portrayal in historic

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[43] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 59.

[44] Julie Anderson and Lisa O'Sullivan, "Histories of Disability and Medicine," in *Re-Presenting Disability: Activism and Agency in the Museum*, ed. Richard Sandell, Jocelyn Dodd, and Rosemarie Garland-Thomson (Routledge, 2013), 143–54, 153.

[45] Christopher M. Bell, "I'm Not the Man I Used to Be: Sex, HIV, and Cultural 'Responsibility,'" in *Sex and Disability*, ed. Robert McRuer and Anna Mollow (Durham N.C.: Duke University Press Books, 2012), 244, emphasis mine.

records (not limited to natural history museums) and their experiences in archival spaces, and thus think about the possibilities for intervention.

Study Design

Semi-structured interviews were conducted with 10 disabled scholars, artists, activists and community members, who have conducted research around disability in archives. This study has been approved by UCLA's Institutional Review Board (IRB).[46] For accessibility reasons unique to the disabled community, the interviews were conducted through different methods depending on what each interviewee preferred: video, phone, and in-person. Video (Skype and Zoom) and phone interviews were the primary method selected for this study, as they are accessible ways for disabled people from anywhere in the world to participate. Skype and Zoom offer video, sound, and text communication options, which make interviews accessible for those who are non-verbal, use American Sign Language (which the researcher is fluent in) and who may prefer to respond in writing. Phone calls provide a space for those who do not want to communicate visually or do not prefer face-to-face interaction, while still offering a method of connecting to people anywhere in the world. One-on-one in person interviews, hosted in a private office at UCLA, were also an option for interviewees in the Los Angeles area who preferred meeting in person, although all interviews were conducted remotely. Having these options allowed more participants to participate in ways that are specific to their access needs and best suited to their ways of communication.

The interviews lasted no more than 90 minutes, were audio-recorded—with consent from the interviewee—by two different devices (in anticipation of technical difficulties), and then

[46] This research was made possible through the Graduate Summer Research Mentorship (GSRM) Award, at University of California Los Angeles in Summer 2018.

were transcribed using a secure transcription service, Temi. I chose to not video record the interviews because, as gesture analysis is not part of this study and the audio serves as the primary data needed for this study, video recording is unnecessarily invasive.[47] Additionally, audio recording had the great advantage of allowing me to make eye contact with and respond thoughtfully to participants since I did not have to take as many notes and could still be able to quote people directly. Morse supports this in stating that "The more fully and accurately any interview can be recorded in the respondent's own words, the better analysis and conclusions will be."[48] Respondents were not asked to reveal any information about their disabilities, but were asked to reflect on their experiences, thoughts, and feelings around researching people with disabilities represented, misrepresented or not represented in mainstream archives.

The discussions were semi-structured as to rely on a guiding set of questions, while allowing the conversation to evolve depending on each participant's personal experiences. A detailed protocol including guiding questions is located in Appendix A. The questions and themes had an open structure and serve as a guide for open-ended conversations, ensuring that all informants addressed similar topics, but also felt free to express other thoughts and feelings while allowing for unplanned probing questions from the researcher.[49]

The interview questions primarily focused on the concept of misrepresentation: how participants feel about seeing themselves represented or misrepresented in history, while also addressing the process of using archives in general. This allowed the research to address the

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[47] Margaret A. DuFon, "Video Recording in Ethnographic SLA Research: Some Issues of Validity in Data Collection," *Language Learning & Technology* 6, no. 1 (2002): 40–59.

[48] Margaret Slater, "Qualitative Research," in *Research Methods in Library and Information Studies*, ed. Margaret Slater, First Edition edition (Facet Pub, 1990), 114.

[49] J.M. Morse, "The Implications of Interview Type and Structure in Mixed Method Designs," in J.F. Gubrium, et al, eds., The Sage Handbook of Interview Research: The Complexity of the Craft (Thousand Oaks: SAGE, 2012), 193-204.

complex experiences of disabled people in navigating archives and their systems, who may be excluded from participating in archival research, as well as the affective responses of the disabled community around how they are represented in history. Interviews not only allow for flexible conversation and follow up questions, but also for the researcher to form relationships with interviewees. As I am part of the disabled community, I understand scholarship to be part of community-building.

Participant selection

Research participants met the following criteria:

a) self -identify as disabled;

b) conducted research in an archive (such as a history or art museum archives, university special collections, library archive, or institution's archive) and found records about people with disabilities;

c) be 21 years or older at the time of recruitment.

To recruit participants, I emailed people in my personal and professional networks asking them to forward the recruitment email to friends and colleagues, posted on social media to be widely shared, and also contacted disability-centered organizations (such as the Disability Visibility Project) to share the call for participants. This snowball sample—community members recommending other participants—provided me with a mixed group of scholars and non-academic disabled people who have worked with archives in various capacities. Potential participants contacted me directly via email to confirm their interest in participating in the study or ask any questions related to the study. Once contacted, I confirmed that the participants met

the requirements of the study, understood the intention of research and the scope of the consent form, as well as expressed any access needs and preferred interview method.

Confidentiality & Consent

Each interviewee read and signed a consent form (Appendix B) before the beginning of each interview, agreeing to participate in the interview and have it be recorded. They were asked to provide their full name on the consent form, but had the option to be identified by name, choose an alias, or be cited confidentially in any dissertation chapters, published manuscripts, or presentations. Prior to the interview, I provided the selected participants with information found on the consent form: the purpose of the study, the length of time of the interview, confidentiality, the risks and benefits, their options if they decide to withdraw their participation, and contact information. Immediately before each interview began, I reviewed the consent form in the presence of each participant, encouraged participants to ask any questions, and checked in about their consent during the interview. Also at the beginning of each interview, when going over the consent form, I also asked each interviewee for a short description of their positionality, how they would like to be described in writing, while also encouraging them to reflect on their identities (for example, marking their whiteness). I use these descriptions in Chapter Three and abbreviate them in Chapter Six.

As consent is ongoing, I continue to check in with each interviewee about the work that I produce. Each interviewee had an opportunity to read, edit, and review both dissertation chapters as well as a published article[50] that used the interview data and again could opt to be cited as an

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[50] Gracen M. Brilmyer, "'It Could Have Been Us in a Different Moment. It Still Is Us in Many Ways': Community Identification and the Violence of Archival Representation of Disability," in *Sustainable Digital Communities*, ed. Anneli Sundqvist et al., Lecture Notes in Computer Science (Cham: Springer International Publishing, 2020), 480–86, https://doi.org/10.1007/978-3-030-43687-2_38.

alias or confidentially. Furthermore, as I understand this research to not only be community-based but also community building, after all 10 interviews were complete, I emailed each participant to get their consent to connect them as a cohort. Currently, 8 out of 10 participants have been connected with one another via email. All interview transcripts are stored on Box at UCLA, a secure cloud-based file sharing and storage service.

Historical methods

Also under the theory building methodology, my second method, historical methods, compliments the empirical research by investigating the case study of the Field Museum through archival materials. As Mortensen tells us, "Historical examination should not be seen as separate from theoretical enquiries… History should be approached not just out of antiquarian interest, but because it can shed light on contemporary concerns. Since archives are historical products, and we are part of that history, bringing that history to awareness can provide insights that make us better able to cope with contemporary concerns."[51] Graeme Johnson emphasizes how many "researchers tend to focus excessively on the future and neglect the relevance of the past. Yet the study of history provides a deep understanding of individuals, societies, organizations, and global structures in the hope of enlightening and improving the present."[52] In order to understand current phenomena, and work towards building a more just future, one must consider the past and how systems and attitudes build upon one another. Moreover, Johnson points out how evidence is rarely self-evident, and requires interpretation skepticism, disentanglement, and explanation. Johnson explains that "Historical writing is a product of a struggle between

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[51] Preben Mortensen, "The Place of Theory in Archival Practice," *Archivaria* 47, no. 0 (February 16, 1999): 21.

[52] Graeme Johnson, "Researching History," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 267–86, 267.

imagination and evidence."[53] Johnson lays out the process of detecting relevant documents (and the lack thereof), approaching them with skepticism, disentangling broad narratives to locate more granular narratives, knowing when to clarify certain aspects and look for more, and finally storytelling of the evidence you have found.

By using historical methods, primarily archival research, Aimi Hamraie highlights the importance of a historical epistemology of disability, as it "places the models framework within broader conversations in the history and philosophy of science in order to foreground the constructed, contested, and contingent nature of systems of knowledge about disability."[54] Through this work they show how assumptions around how bodies should move through space—whether practices ignore disabled bodies or attempt to rehabilitate them—become ingrained within physical spaces, which further influence future assumptions. By using historical methods to retell the history of design, they excavate interlocking narratives of ergonomics, eugenics, rehabilitation, and justice, all of which influenced how spaces were built and therefore bodyminds are understood (which, in turn, influence how spaces are built).[55]

Archival research often lends itself to historical methods, as many scholars inside and outside of archival studies have come to be critical of the ways in which archives imbue power into public memory. Anne Gilliland and Sue McKemmish, in their chapter *Archival and Recordkeeping Research*, cite historiography or historical methods as one of several research

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[53] Graeme Johnson, "Researching History," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 267–86, 272.

[54] Aimi Hamraie, "Historical Epistemology as Disability Studies Methodology: From the Models Framework to Foucault's Archaeology of Cure," *Foucault Studies* 0, no. 19 (June 17, 2015): 108–34, https://doi.org/10.22439/fs.v0i19.4827, 111.

[55] Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (University of Minnesota Press, 2017).

methods for archival studies. They note how this method can illuminate recordkeeping and archival practices throughout time, as well as the "exploration of archives, power, and memory."[56] Recent scholarship has challenged traditional ideals of neutrality within archives.[57] and has explored how value is embedded in archival processes through the assumption that certain records have value for future use.[58]

Archival material, as seen in much archival literature, provides evidence for the interpretation and reinterpretation of the past and of history. For example, scholars such as Ciaran Trace have explored how value is embedded in the process of appraisal by assuming certain records have value for future use.[59] Trace, through looking closely at archival appraisal literature, highlights evidence that "[n]otions of value and worth have differed across time and across different social, political, and cultural contexts as we constantly reinvent ourselves and repurpose ideas and values in response to change."[60] Melissa Adler, by tracing the history of "paraphilias", demonstrates how the archaic language of the Library of Congress not only

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[56] Anne J Gilliland and Sue McKemmish, "Archival and Recordkeeping Research," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), p.96.

[57] Verne Harris, "Postmodernism and Archival Appraisal: Seven Theses," *S. A. Archives Journal* 40 (June 1998): 48; Anne Gilliland, "Neutrality, Social Justice and the Obligations of Archival Education and Educators in the Twenty-First Century," *Archival Science* 11, no. 3–4 (November 1, 2011): 193–209, https://doi.org/10.1007/s10502-011-9147-0.

[58] Brien Brothman, "The Past That Archives Keep: Memory, History, and the Preservation of Archival Records," *Archivaria* 51, no. 0 (January 1, 2001): 48–80; Tom Nesmith, "Seeing Archives: Postmodernism and the Changing Intellectual Place of Archives," *The American Archivist* 65, no. 1 (January 1, 2002): 24–41, https://doi.org/10.17723/aarc.65.1.rr48450509r0712u; Joan M. Schwartz and Terry Cook, "Archives, Records, and Power: The Making of Modern Memory," *Archival Science* 2, no. 1–2 (March 1, 2002): 1–19, https://doi.org/10.1007/BF02435628; Ciaran Trace, "On or Off the Record? Notions of Value in the Archive," in *Currents of Archival Thinking* (Santa Barbara, Calif.: Libraries Unlimited, 2010), 47–68.

[59] Ciaran Trace, "On or Off the Record? Notions of Value in the Archive," in *Currents of Archival Thinking* (Santa Barbara, Calif.: Libraries Unlimited, 2010), 47–68.

[60] Ciaran Trace, "On or Off the Record? Notions of Value in the Archive," in *Currents of Archival Thinking* (Santa Barbara, Calif.: Libraries Unlimited, 2010), 47–68.

reinforces stigma around queerness, but also limits intelligibility and findability for LGBTQ communities.[61] These works are situated among vast scholarship that has uncovered the notion that there are constructions of value, by certain people and for certain people, within all archival facets and by utilizing records to critically address history, we can also untangle the impact of how systems affect people today.

Historical methods not only allow for the reinterpretation of representations, but also the identification and analysis of erasure. Johnson notes that "Not all the evidence can be examined sometimes, often for very practical reasons. Some evidence will have disappeared, or will be secret… Yet the Historian tries to make sense of the whole puzzle of first-hand accounts, that is of primary evidence."[62] Caswell, in her book *Archiving the Unspeakable*, reframes mugshots taken during the Cambodian genocide to demonstrate that much was missing from these narratives. Centering Trouillot's four moments of silencing, she shows how the absence of these narratives proliferate the records and therefore influence how we understand this history of oppression. However, she notes, "silence and agency are two sides of the same coin; the archived mugshots being used to spark narratives are agents with a social life, yet complex layers of silences (of those victims not recorded, those records not archived, those archives not used) are encoded in each moment within this social life."[63] Janette Bastian analyzes records that tell the history of the US Virgin Islands, housed in Washington DC and in Belgium. By addressing the

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[61] Melissa A. Adler, "For Sexual Perversion See Paraphilias: Disciplining Sexual Deviance at the Library of Congress" (THE UNIVERSITY OF WISCONSIN - MADISON, 2012), http://gradworks.umi.com/35/08/3508162.html.

[62] Graeme Johnson, "Researching History," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 267–86, 273.

[63] Michelle Caswell, *Archiving the Unspeakable: Silence, Memory, and the Photographic Record in Cambodia*, 1 edition (Madison (Wis.): University of Wisconsin Press, 2014), 21.

history of colonization through records, she acutely locates the multitude of biases, silences, and violence in these records and their transcriptions.[64] As these works show, historical methods, specifically around records, can also take a critical lens on what might be missing from a record or public memory.

By closely looking at records that tell the history of the Field Museum, this dissertation aims to not only analyze what evidence is present on and around disabled or idealized bodyminds, but also acutely and critically analyze what is missing. By focusing on how notions of disability or ableism may be hidden in aspects of the museum, the Chapter Four and Chapter Five closely analyze moments where disability might be present, even through its absence, as a way to develop archival theory around the erasure of disability in history and demonstrate how archives and records tell partial histories. The archival materials that I use in this research are complemented by other historical documents, especially when researching expansive histories of museum and archival pedagogies and practices as well as disability history more broadly.

Selection of Sites

The Field Museum of Natural History, being the third largest museum of its kind, is my chosen site of research because of its influence in national and global conversations on display, preservation and other museum practices; its historical precedent in standardizing scientific communication; its roots being traceable to the influential 1893 World's Columbian Exposition (WCE); and it's unknown history with disability. I had also worked at the Field Museum, within their insect collections, and was familiar with the museum's history and founding from the WCE.

[64] Jeannette A. Bastian, "Whispers in the Archives: Finding the Voices of the Colonized in the Records of the Colonizer," in *Political Pressure And the Archival Record*, ed. Margaret Procter, Michael Cook, and Caroline Williams (Chicago: Society of Amer Archivists, 2006), 25–43.

As stated in the introduction, 1893 Chicago World's Fair was not only foundational to the development of The Field Museum itself, but also to different museum pedagogies, many of which are continued today. The WCE brought millions of visitors to Chicago to witness spectacularized 'living museums' as well as demonstrations of technological and biological western knowledge. The Fair exhibited such spectacles of culture through preserving specimens and objects first to be displayed in reconstructed scenes and display cases, frozen in time for the consumption of The Fair's visitors and second to be housed permanently in the museum's collections. Both the display and preservation of objects, animals and people demonstrated a western dominance over cultural and biological differences for the fair's visitors to consume. Although it still remains unclear if disabled people were displayed at the WCE, it had great influence on display practices, ranging from museums, freak shows, and department store windows.[65]

The ways in which the WCE organized knowledge around human variation, as Susanne Belovari shows, influenced how materials are treated today.[66] Belovari describes the colonial and western ideals of the WCE—that were later taken up and perpetuated by archivists and museum staff—influenced the treatment, representation, and collecting activities around Native American materials. She states that "professional choices taken by the relevant actors smoothly fit within the colonial evolutionary context of the Exposition, The Field [Museum], as well as its donors,

[65] Katherine Ott, "Disability and the Practice of Public History: An Introduction," *The Public Historian* 27, no. 2 (2005): 9–24, https://doi.org/10.1525/tph.2005.27.2.9.

[66] Susanne Belovari, "Professional Minutia and Their Consequences: Provenance, Context, Original Identification, and Anthropology at the Field Museum of Natural History, Chicago, Illinois," *Archival Science* 13, no. 2 (June 1, 2013): 143–93, https://doi.org/10.1007/s10502-013-9202-0.

managers, and staff," and impact how materials are understood today.[67] She concludes by emphasizing that:

> "Failing to think of our work and ourselves as historical products has major implications for the work we do and the materials we care for. This is particularly true for archives where provenance, original identifications, as well as records context are paramount in order to situate individual items and make them meaningful in a somewhat elusive but significant 'original' sense."[68]

The Field Museum currently resides on the traditional homelands of the Three Fires Confederacy: Ojibwe, Odawa, and Potawatomi. Including many of the Chicago World's Fair collections, The Field Museum currently houses over 40 million specimens and artifacts within its collections, which are preserved for long-term research and use. James Hanken, director of the Museum of Comparative Zoology at Harvard University in Cambridge, Massachusetts, is quoted in saying that "It's one of the great research institutions in comparative zoology, biodiversity and natural history, and it has been one of the leading centres of research for more than 100 years."[69] At any given time, the museum hosts around 50–60 graduate students from the University of Chicago and other area universities to work with curators, use labs, and perform

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[67] Susanne Belovari, "Professional Minutia and Their Consequences: Provenance, Context, Original Identification, and Anthropology at the Field Museum of Natural History, Chicago, Illinois," *Archival Science* 13, no. 2 (June 1, 2013): 143–93, https://doi.org/10.1007/s10502-013-9202-0, 185.

[68] Susanne Belovari, "Professional Minutia and Their Consequences: Provenance, Context, Original Identification, and Anthropology at the Field Museum of Natural History, Chicago, Illinois," *Archival Science* 13, no. 2 (June 1, 2013): 143–93, https://doi.org/10.1007/s10502-013-9202-0, 186.

[69] Helen Shen, "Chicago's Field Museum Cuts Back on Science," *Nature News*, accessed November 17, 2018, https://doi.org/10.1038/nature.2012.12105.

research,[70] along with post-doctorates, graduate student fellows, undergraduate and high school interns, and many other visiting researchers.[71] The museum also has a large public-facing presence, reporting 1.65 million visitors in 2016.[72] Not only has the museum had an influence on standards of preservation, display, and other scientific discourses, but also, given its size and history, it continues to be an international leader in such techniques and research.

Having personally worked in the biological collections of The Field for a cumulative 5 years, I have an intimate knowledge of the museum's collections, curation policies, and institutional history. Before beginning this research I had already been exposed to parts of their archives, which cover the museum's founding from and after the Chicago World's Fair, the many museum-funded expeditions to other countries and cultures, and the construction of dioramas and displays of museum material.

Selection of Materials

Materials were primarily located in three archives, all of which contain extensive records on the history of the Field Museum: The Field Museum of Natural History Archives, the Chicago History Museum Research Center Archives, and the Harold Washington Library Special Collections, all of which are located in Chicago, Illinois and hold extensive collections on the history of The Field Museum, including the WCE. These three sites contain much documentation spanning the 1890's through present day and include historical material such as pamphlets and

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[70] Helen Shen, "Chicago's Field Museum Cuts Back on Science," *Nature News*, accessed November 17, 2018, https://doi.org/10.1038/nature.2012.12105.

[71] "Research Scholarships and Grants," Text, Field Museum, January 13, 2011, https://www.fieldmuseum.org/about/careers/research-scholarships-and-grants.

[72] Steve Johnson, "Chicago Museums Set Attendance Records in 2016," chicagotribune.com, January 2017, https://www.chicagotribune.com/entertainment/museums/ct-museum-attendance-chicago-ent-0126-20170125-story.html.

promotional material, letters, photographs of exhibitions and collecting expeditions, and specimen records. Additionally, the Chicago Tribune Online Archives, which have digitized their collections, have been searched for records on The Field Museum, The Chicago World's Fair, and disability in the late nineteenth and early twentieth century. At these sites as well as at the Seaver Center for Western History Research at The Natural History Museum of Los Angeles County, UCLA Library Special Collections, and UC San Diego Special Collections and Archives—which contain additional collections on The 1893 World's Fair—I closely analyzed the history of The Field Museum and look for traces of disability. These archival materials are additionally complemented by other historical documents—as I researched the history of disability more broadly as well as traced expansive histories of museum and archival pedagogies and practices, I found that situating records within other historical material could compliment the contents of records and allow for them to be historically situated. I therefore use additional primary documentation, scholarly articles, and other online sources that facilitate contextualizing records.

Materials were analyzed for their proximities to disability: I kept in mind how intersecting and interlocking systems of oppression operate. Through my knowledge of disability history, it's spectacularization, criminalization and medicalization, I could consider how materials that didn't explicitly depict disabled people could still be used to portray a history of disability. For example through official museum records, published works, unpublished manuscripts, advertisements, journal entries, and photographs, I conducted a preliminary tracing of the history of the museum to the 1893 World's Fair and assessed attitudes about preservation of specimens and objects. One book, *Portrait Types Of The Midway Plaisance*, seems exemplary of the attitudes of the people who had power in the production of the fair. The 1894 album is, "A

collection of Photographs of Individual Types of various nations from all parts of the World who represent, in the Department of Ethnology, The Manners, Customs, Dress, Religions, Music and other distinctive traits and peculiarities of their Race."[73] A type specimen, defined by the International Commission on Zoological Nomenclature (the recognized body to standardize terms in many biological fields) is a specimen that becomes a representative of its group by exemplifying the characteristics of that group.[74] The term "type" is predominantly used in the biological sciences today to name, define and publish on new animal and plant species, however, the *Portrait Types Of The Midway Plaisance* demonstrates how it was deployed to define physical and cultural differences between humans. The book features nearly 100 photographs with accompanying descriptions of many of the people put on display at the World's Fair. To name human difference, as we see with race, gender, sexuality, and medicalized disability, is often defined by its deviation from a white, able-bodied, cis-gendered male. Melissa Adler notes how the "universalization of whiteness and the marking of nonwhite as exceptions to an assumed rule have, in fact, perpetuated the invisibility and dominance of whiteness."[75] Moreover, as Duff and Harris articulate, "[w]hat we name we declare knowable and controllable."[76] In *Portrait Types Of The Midway Plaisance*, the treatment of humans as specimens, to be discovered, named, and displayed highlights the immense amount of western dominance exerted over any

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[73] F. W. (Frederic Ward) Putnam, *Portrait Types Of The Midway Plaisance*, 1894, http://archive.org/details/PortraitTypesOfTheMidwayPlaisance.

[74] International Commission on Zoological Nomenclature, "International Code of Zoological Nomenclature, Fourth Edition," January 1, 2000, http://www.iczn.org/iczn/index.jsp.

[75] Melissa Adler, "Classification Along the Color Line: Excavating Racism in the Stacks," *Journal of Critical Library and Information Studies* 0, no. 1 (January 29, 2017), http://libraryjuicepress.com/journals/index.php/jclis/article/view/17, 5.

[76] Wendy M. Duff and Verne Harris, "Stories and Names: Archival Description as Narrating Records and Constructing Meanings," *Archival Science* 2, no. 3–4 (September 2002): 263–85, doi:10.1007/BF02435625.

'othered' body. The Fair, like the publications that resulted from it, created spectacles around difference and, through such displays, asserted a western hierarchical ontology that placed whiteness as the ideal. Records such as this serve as evidence of the colonial attitudes of the world's fair that were concerned with identifying difference. Through framing these records within archival theory as well as disability studies, those historical ties can be resurfaced, complicated, and understood as foundational to the establishment of present day policies around preservation. Materials, such as these, were selected based on their proximity to disability: including but not limited to: notions of ideal bodyminds (such as 'perfect specimens'), mentions of accessibility at the museum or The 1893 World's Fair (i.e. wheelchairs, disabled patrons, etc.), explicit documentation disabled people (visitors, in exhibitions, etc.), and mentions of medical discourse as part of the history of the museum or scientific knowledge.

When performing archival research, I gave each folder in a collection a unique identifying number so that I can accurately reference and connect all of my data collection techniques. This number was included in the photographs I took (with permission of each archives) of the records that feel pertinent to my research, and the photos are stored on my personal laptop—organized within Tropy—as well as in Box Drive. I recorded each folder, the collection's details, and its accompanying number within a spreadsheet and also took extensive hand-written notes, recording a fonds' unique identifying number. The photos, spreadsheet and notes all work to substantially document my research findings and process.

Data Analysis

The data that is collected both through the interviews and historical methods will be coded and analyzed in an iterative manner, described by Lofland and Lofland as an "inductive

and emergent process in which the analyst is the central agent.[77] Kimberly Anderson highlights how, "[h]istorical evidence is… used for interpretation and inference, but may not be considered outright proof. Rather, it is the task of the interpreter (usually a scholar) to analyze and deduce larger scenarios from the evidence that remains."[78] A close analysis through using critical theory allows for me to locate key themes, truth claims, contradictions, and absences as well as apply my knowledge of contemporary museum practices to trace their foundations to the 1893 World's Fair. Furthermore, a close reading of the labels, captions, images, and promotional materials in the archives allows me to pay attention to not only the visual material that the museum constructed in its own image, but also the practices and technologies that produced visual material.

I coded the historical documents and interview transcripts. Coding, "the process of categorizing and sorting data," is used as a device to "label separate, compile, and organize the data" as well as to "summarize, synthesize, and sort many observations made of the data."[79] Although much of my cited literature on coding comes from grounded theory, I have chosen not to use grounded theory explicitly, as it implies strictly allowing the hypotheses to emerge from the data (from the ground up).[80] My project, on the other hand, is deeply influenced by my personal experiences working in archives, the disability community with whom I've discussed

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[77] John Lofland et al., *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*, 4 edition (Belmont, CA: Wadsworth Publishing, 2005), 181.

[78] Kimberly D. Anderson, "The Footprint and the Stepping Foot: Archival Records, Evidence, and Time," *Archival Science* 13, no. 4 (2013), https://works.bepress.com/kimberly_anderson/3/.

[79] Kathy Charmaz, "The Grounded Theory Method: An Explication and Interpretation," in *More Grounded Theory Methodology: A Reader*, ed. Barney G. Glaser (Mill Valley, CA: Sociology Pr, 1994), 95–115, 97-98.

[80] Barney G. Glaser and Anselm L. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Transaction Publishers, 2009).

archives with, and the field disability studies that critically addresses archives and history. Therefore, I formed hypotheses both on how the misrepresentation or erasure of disability may affect the community as well as how critical proximity may serve as a critical lens for reintroducing disability into historical narratives. However, as coding, developed in grounded theory is concerned with allowing for hypotheses to emerge directly from the data, especially where little is known about a particular situation or phenomenon, these coding techniques are valuable to this project and allowed for the data to shift my hypothesis and reveal unanticipated specificities of the project.

I coded the documents using constant comparative analysis and coding procedures developed in grounded theory such as open coding, axial coding, inductive coding, and selective coding aligning with methods developed by Strauss and Corbin,[81] whereby I derived and developed concepts from the data I have gathered. Specifically, I drew on the technique of open coding, as "in the beginning, analysts want to open up the data to all potentials and possibilities contained within them."[82] Codes were developed through the direct examination of materials and transcripts asking questions[83] such as: What is this? What does it represent? What archival and museum processes are being represented? What archival and museum processes have influenced this? What does the order or the records tell me about this history? What records might I relate to this?

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[81] Anselm Strauss and Juliet Corbin, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, 2 edition (Newbury Park, Calif.: SAGE Publications, Inc, 1990).

[82] Ibid.

[83] John Lofland et al., *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*, 4 edition (Belmont, CA: Wadsworth Publishing, 2005)

Once initial codes were created, I reviewed my list of codes to locate prevalent themes in the interview transcripts as well as the archival materials to identify "which topics and questions are being treated more than others."[84] As some codes emerge as more dominant than others, I respected how this process "tend[s] to be iterative, with various elements in the research being interwoven: the development of one influences decisions about the others," and new codes may emerge as I analyzed the data. Emerging from the interview data were two prominent themes: one around the ways in which disabled people related to their representation in archival materials (as illustrated in Chapter Three) and another around how they experienced accessibility and inaccessibility of archives (discussed the Chapter Six). From the archival literature, I noticed themes around archival processes such as description, organization, and preservation which helped me draw connections of disability within this history. The theme of organization took precedence in Chapter One as a theoretical and actualized model of provenance; the theme of description is explored and evaluated through language and systems in Chapter Four; and the theme of preservation emerged as a final concept to think about disability in history in Chapter Five. I also made note of which codes are present across both data collection methods.[85]

The triangulation of these two different methods demonstrate "converging lines of inquiry,"[86] on the subject of the representation of disability in history. Triangulation, or "using more than one research method in measuring the same object of interest," helps to not only provide a more robust dataset from which to draw themes, but also reduces potential bias from a

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[84] John Lofland et al., *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*, 4 edition (Belmont, CA: Wadsworth Publishing, 2005), 192.

[85] Kirsty Williamson, "Research Concepts," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 3–23, 14.

[86] Robert K. Yin, *Case Study Research: Design and Methods*, 5 edition (Los Angeles: SAGE Publications, Inc, 2013).

single method of data collection.[87] As Blaikie notes, "it has been argued that the deficiencies of any one method can be overcome by combining methods and thus capitalizing on their individual strengths."[88] The triangulation of methods will also allow for the triangulation of a wide array of data:[89] historical records and archival sources, disabled people's personal descriptions of their experiences, as well as extensive theoretical and subject-specific literature. Moreover, triangulation plays a part in establishing trustworthiness, constructed through *credibility*—where findings reflect the multiple lived realities of subjects—*transferability*—where similarities between data can be more broadly applied, improving external validity—*dependability*—that variance will be explained and analyzed—and *confirmability*—the acknowledgement that although researchers are influenced by their data, the results are not simply formed through their own biases, agendas, and perspectives.[90] Establishing trustworthiness through triangulation is central to this project as it allows for the board theorization of major themes within these data, while also maintaining a focus on the specifics and differences across data, individuals, and histories.

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[87]Martin Oppermann, "Triangulation — a Methodological Discussion," *International Journal of Tourism Research* 2, no. 2 (March 1, 2000): 141–45, https://doi.org/10.1002/(SICI)1522-1970(200003/04)2:2<141::AID-JTR217>3.0.CO;2-U.

[88] Norman W. H. Blaikie, "A Critique of the Use of Triangulation in Social Research," *Quality and Quantity* 25, no. 2 (May 1, 1991): 115–36, https://doi.org/10.1007/BF00145701. 115.

[89] Kirsty Williamson, ""Ethnographic Research," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013)298.

[90] Kirsty Williamson, "Research Concepts," in *Research Methods: Information, Systems and Contexts*, ed. Graeme Johanson and Kirsty Williamson (Prahran, VIC: Tilde Publishing and Distribution, 2013), 3–23, 14.

Limitations of the Study

External reliability, the generalizability of the study group to the population at large or to other populations,[91] will be difficult to verify, as the interviews will produce data specific to the disabled community and the historical methods will reveal a history specific to The Field Museum. The sample size of the 10 interviews is not representative thus the data will not be generalizable, and I therefore aim to gather detailed data to build theory in an area where little is yet known. Moreover, this project is more concerned with an in-depth analysis and providing deep, rich narratives from qualitative research, rather than acquiring a large quantity of data that can be generalizable. Reliability will also be difficult to test, since the personal nature of the interview conversations, location of historical records as well as my interpretations of the data may make the method and subsequent interpretations fairly difficult to replicate, although future research may access the records.[92] However, the limits of the external reliability of this study are a trade off for the significance of the strong internal validity.

Taking a interpretivist approach to qualitative research, I not only recognize that researchers cannot be objective, but also that as I analyze the interactions between myself and participants and myself and the archival material,[93] I listen to perspectives, silences, and build analysis and theory from the people being studied.[94] These techniques allow for me to reflect on themes that show up in the data, while also distinguishing between individual opinions and

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[91] William R. Shadish, Thomas D. Cook, and Donald T. Campbell, *Experimental and Quasi-Experimental Designs for Generalized Causal Inference*, 2 edition (Boston: Wadsworth Publishing, 2001).

[92] Earl L. Babbie, *The Basics of Social Research*, 7 edition (Boston, MA, USA: Wadsworth Publishing, 2016).

[93] Alison Jane Pickard, *Research Methods in Information, Second Edition*, 2 edition (Chicago: ALA Neal-Schuman, 2013).

[94] Kirsty Williamson and Solveiga Saul, “Ethnography,” in *Research Methods for Students, Academics and Professionals: Information Management and Systems* (Elsevier, 2002), 177–93.

overarching themes, as attention will be given to opinions that do not fit the overall theories/themes.[95]

[95] J. Kitzinger, "Qualitative Research. Introducing Focus Groups.," *BMJ : British Medical Journal* 311, no. 7000 (July 29, 1995): 299–302.

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Chapter Three: People
"It felt like everything": A perverse absent-presence and the creation of archival interdependence

Introduction

It means everything to begin this dissertation with the voices of my communities, of living disabled people. My whole life my health and disabilities have fluctuated—I've had varying levels of pain, mobility, and cognition. But more importantly, my relationship with an identity as Disabled, as sick, as chronically ill has and continues to fluctuate. My identity has been shaped through relationships with friends, mentors, collaborators, and community members—many of which were disabled, some of which worked in the field of disability studies, some who I came to know well, others who I shared space with occasionally. Through these crip communities in Chicago, the Bay Area, Los Angeles, and online, I became involved in organizing events, art, activism, and community-based projects. Witnessing performances by Sins Invalid and AXIS Dance Company; attending and organizing meetings around access and technology with the Bay Area Accessibility and Inclusive Design meet up and Accessibility Camp Bay Area; advocating for access to museum and academic events for and with d/Deaf and hard of hearing comrades; volunteering for, attending, and witnessing powerful conversations around Disability Justice at events such as *Disability Incarcerated*, *Disability as Spectacle*, *Sick Fest* and *Bay Area Day of Mourning*; collaborating on and experiencing community care work through Sick and Disabled UC Coalition (formerly Crips4COLA) and contributing to long distance care networks; and building community through emails, social media, phone calls with friends-of-friends, academic connections, and other disabled people—all of these experiences, conversations, knowledges, and people have shaped my identity as Disabled and facilitated my deeper, constantly growing understanding of disability as political, historical, cultural, and

relational. I've experienced what Stacy Park Milbern and Leah Lakshmi Piepzna-Samarasinha call *crip doulaing*—"crip mentoring and assisting with birthing into disability culture/community, different kinds of disability, etc…. Naming disability as a space we can be born into, not alone but supported and welcomed by other disabled people"[1]—throughout my life and have been around disabled people who have shaped and continue to shape who I am, without which this project would not be possible. In other words, disabled communities have shaped who I am and for me, community is a central aspect of being disabled.

This chapter outlines a central piece of what a crip provenance includes—*people*: not only the subjects of records but those who experience them, their contents, context, and absences. As I begin to build this constellation of connections, proximities, and relationships that occur because archival materials are always already dispersed, duplicated, and incomplete, I start with our experiences of records in the present moment: how disabled communities relate across time. The materials that represent disability are located across many different archives, sometimes unnamed, and disabled people encounter them in vastly different environments. Therefore this chapter, using the data collected through interviews with disabled archival users, investigates the multiple ways in which disabled users of archives are impacted by seeing themselves represented, underrepresented, and erased in history. While articulating these relationships, this chapter also illuminates how, by even doing this research, I am in community with disabled people, and my community is expanding further through these new connections, conversations, and networks with disabled people. While I'm describing the relationships of the interviewees to historical documentation of disability, I'm simultaneously describing my relationships to each of them, all of them as a cohort, and all of us to history.

[1] Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver: Arsenal Pulp Press, 2018), 240-1.

In this chapter, I will first cover the existing literature around disability and archives. I'll illustrate how disabled people have a long history of being represented in ways that often erase their subjectivity as well as how such records impact the ways in which disabled lives are represented and their histories are told. I'll then show how community is a central part of survival for many sick and disabled people. Given that archival studies has revealed the ways in which some marginalized identities are affectively impacted by under- or mis-representation in mainstream archives, I will illuminate four key findings from disabled archival users. First, although disabled people may be familiar with dominant (problematic) forms of the representation of disability, participants still had an emotional response to witnessing people with disabilities portrayed in problematic ways as well as seeing the violence of the past. Second, considering the dominant forms of representation of disability, disabled people come to expect to be erased in history. Third, they meet this type of misrepresentation and erasure with a critical and political lens. And lastly, archival representation has complex affective impacts on disabled archival users: participants not only felt a deep connection with histories of institutionalization, incarceration, and discrimination, but also understood these records as having the potential to be activated as evidence of the ways in which disability is perceived and understood. This research demonstrates the necessity for disabled people to see themselves in history and underscores how disabled people can feel a deep sense of community not only with current communities—which is so vital to our existence—but also with disabled people across time, thus illustrating an *archival interdependence*.

Disability Representation in Archives & Archival Affect

When thinking about the history of disability, I am drawn to consider the ways in which disabled people have historically been documented, surveilled, and therefore represented in

records. For example, Susan Schweik's work on late-nineteenth and early-twentieth century American legislation, often named "the Ugly Laws," explicitly shows how records were produced for the criminalization and containment of disabled and other marginalized bodies.[2] Although the Ugly Laws frequently centered around disability, they were wielded as a way to criminalize many non-normative bodyminds[3] and reinforce stereotypes of disabled people as 'dangerous' or 'dirty'. Because of the laws, records were produced through the arrest and institutionalization of people found "unsightly". Records—such as arrest records, asylum documentation, city and state ordinances, and newspaper articles—not only were created because of societal discrimination but also reinforced a public acceptance of the criminalization of disabled people, poor people and people of color.[4] Attitudes around disability have become embodied within records as people were arrested, institutionalized, experienced medical treatment, as well as how "those benefiting by a power structure based upon white privilege us[ed] medical and psychiatric diagnoses to manufacture 'truths' of racial inferiorities."[5] In other words, some historical records around disability, like those produced because of the ugly laws, are produced by people in power and document disabled people according to negative stereotypes, which often lack disabled perspectives.

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[2] Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010).

[3] Sami Schalk, *Bodyminds Reimagined: (Dis)Ability, Race, and Gender in Black Women's Speculative Fiction* (Durham: Duke University Press Books, 2018).

[4] Jacobus tenBroek, "The Right to Live in the World: The Disabled in the Law of Torts," *California Law Review* 54, no. 2 (May 31, 1966): 841, https://doi.org/10.15779/Z384J44; Nirmala Erevelles, "The Color of Violence: Reflecting on Gender, Race, and Disability in Wartime," in *Feminist Disability Studies*, ed. Kim Q. Hall (Bloomington: Indiana University Press, 2011).

[5] Michelle Jarman, "Coming Up from Underground: Uneasy Dialogues at The. Intersections of Race, Mental Illness, and Disability Studies," in *Blackness and Disability: Critical Examinations and Cultural Interventions*, ed. Christopher M. Bell (East Lansing: Michigan State University Press, 2012), 19.

Within information studies, scholars have begun to address disability as an axis of identity to analyze as well as to employ disability studies as a theoretical lens through which to understand historical records. Focusing on classification systems within libraries and archives, Sarah White as well as Melissa Adler, Jeffrey T. Huber, and A. Tyler Nix utilize disability studies to problematize how disabled people are represented, categorized, and oppressed through archival and library processes. White and Adler et. al.'s works show how, historically, records have been used to identify, document, and control disabled as well as other marginalized bodies: White describes how ableism produced records that in turn informed social understanding of who was 'defective'.[6] And library classification systems and subject headings, as Adler et. al. demonstrate, can reproduce dominant, pathologizing discourses around disability by not only medicalizing it, but maintaining notions that "people with disabilities [are] diseased and/or dependent."[7] Both works, by utilizing disability studies, trace the classification of disability as informed by and associated with criminology, class, race, and other 'social problems' as well as embedded in legacy systems that produced and (re)produce hierarchies of power.

In many of these historical representations of disabled people, records impact the ways in which lives are represented and histories are told. Much documentation produced around disability is told by those in power to write history, often "advocating [for] the segregation of the feebleminded from society, their sterilization, or even extermination."[8] Susan Wendell tells us

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[6] Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," *The American Archivist* 75, no. 1 (April 1, 2012): 109–24, doi:10.17723/aarc.75.1.c53h4712017n4728.

[7] Melissa Adler, Jeffrey T. Huber, and A. Tyler Nix, "Stigmatizing Disability: Library Classifications and the Marking and Marginalization of Books about People with Disabilities," *The Library Quarterly* 87, no. 2 (March 16, 2017): 117–35, doi:10.1086/690734.

[8] James W. Trent, "Defectives at the World's Fair: Constructing Disability in 1904," *Remedial and Special Education* 19, no. 4 (July 1, 1998): 201–11, https://doi.org/10.1177/074193259801900403, 208.

that "The lack of realistic cultural representation of experiences of disability not only contributes to the 'Otherness' of people with disabilities, by encouraging the assumption that their lives are inconceivable to non-disabled people, but also increases non-disabled people's fear of disability by suppressing knowledge of how people live with disabilities."[9] As much of the aforementioned work highlights, the voices of those whose lives were affected by such representations are missing from the records and thus from history.[10] Not only has disability had a fraught relationship with archives as archival materials were often produced as a way to identify, control, profit from, and oppress disabled people (in stereotypical ways) but they also, given such narratives' preservation in archives—coupled with the lack of archival interventions—have the potential to maintain harmful rhetorics that continue to impact disabled people's lives today.

Recent literature in archival studies has revealed the ways in which some marginalized identities are *affectively* impacted by under- or mis-representation in mainstream archives (read: large institutions and cultural organizations that often purport to serve a general public). Michelle Caswell, Marika Cifor, and Mario H. Ramirez utilize George Gerbner's notion of "symbolic annihilation"—where members of underrepresented groups feel essentially erased in history through the ways in which they are not represented in mainstream media—to frame the impact of archival representation on communities marginalized by race, ethnicity, sexuality and gender.[11] Through empirical data collected through focus groups consisting of users of community-based archives, they note that participants' "…responses indicate a sense of alienation, isolation, and

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[9] Susan Wendell, "The Social Construction of Disability," in *The Rejected Body: Feminist Philosophical Reflections on Disability*, 1 edition (New York London: Routledge, 1996), 35–56, 43.

[10] Chloe Brownlee-Chapman et al., "Between Speaking out in Public and Being Person-Centred: Collaboratively Designing an Inclusive Archive of Learning Disability History," *International Journal of Heritage Studies* 24, no. 8 (September 14, 2018): 889–903, https://doi.org/10.1080/13527258.2017.1378901.

[11] Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (Spring/Summer 2016): 58.

misrepresentation in mainstream repositories that is consistent with the concept" of symbolic annihilation. They describe the affective impacts of how marginalized groups feel essentially erased in history through the ways in which they are underrepresented and misrepresented in history. In contrast, Caswell, Alda Allina Migoni, Noah Geraci, and Marika Cifor have investigated not only the ways in which symbolic annihilation in mainstream archives has negative impacts on communities, but also how community-based archives, communities documenting themselves in their own archives, have drastic positive affective impacts—seeing oneself and one's community represented in history can positively inform a feeling of belonging.[12] Along these lines, Chloe Brownlee-Chapman, Rohhss Chapman, Clarence Eardley, Sara Forster, Victoria Green, and Helen Graham have begun to investigate the profound value of disabled people being involved in archival processes to document and complicate historical narratives.[13] Building The Living Archive of Learning Disability History, a collaborative project between disabled people, researchers, designers, health workers, and allies, they illustrate how when disabled people are at the center of archival projects, awareness can be raised around disability history with nuanced narratives. Similarly, Wendy Duff, Jefferson Sporn, and Emily Herron describe how the involvement of survivors of state-enforced sterilization in a community-based archive project could reflect an ethics of care and combat symbolic annihilation.[14] Located alongside this work, this chapter critically examines the impacts of archival misrepresentation and erasure, specifically within disabled communities. Although there are profound positive

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[12] M. Caswell et al., "'To Be Able to Imagine Otherwise': Community Archives and the Importance of Representation" 38, no. 1 (December 1, 2016): 5–26, https://doi.org/10.1080/23257962.2016.1260445.

[13] Chloe Brownlee-Chapman et al., "Between Speaking out in Public and Being Person-Centred: Collaboratively Designing an Inclusive Archive of Learning Disability History," *International Journal of Heritage Studies* 24, no. 8 (September 14, 2018): 889–903, https://doi.org/10.1080/13527258.2017.1378901.

[14] Duff, Wendy, Jefferson Sporn, and Emily Herron. "Investigating the Impact of the Living Archives on Eugenics in Western Canada." Archivaria 88 (November 17, 2019): 122–61.

impacts of different communities representing themselves, I investigate the contrary: the plethora of historical documentation around disability that is often located in mainstream archives.

Disability & the Value of Community

For many d/Deaf, Disabled, Mad, and Sick people, community is a central part of survival. Aimi Hamraie and Kelly Fritsch state that disabled people's "collective experiences and histories have taught us that we are effective agents of world-building and -dismantling toward more socially just relations."[15] And many have emphasized the importance of cross-disability solidarity, comprising communities of many identities. In defining Disability Justice, activist and performer Patty Berne lists the ten (10) principles, one of which is that:

> "We hold a *Commitment to Cross Disability Solidarity*, valuing and honoring the insights and participation of all of our community members and therefore are committed to breaking down ableist / patriarchal / racist / classed isolation between people with physical impairments, people who identify as 'sick' or are chronically ill, 'psych' survivors and those who identify as 'crazy', neurodiverse people, people with cognitive impairments, people who are a sensory minority, as we understand that isolation ultimately undermines collective liberation."[16]

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[15] Aimi Hamraie and Kelly Fritsch, "Crip Technoscience Manifesto," *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (April 1, 2019): 2.

[16] Patty Berne, "Disability Justice – a Working Draft by Patty Berne | Sins Invalid," June 10, 2015, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne.

Mia Mingus reminds us, "***It means something to be disabled. Never forget that***."[17] As disabled people comprise an estimated 15% of the population[18] and "unequivocally… disabled people are everywhere,"[19]it's important to think about our relations to each other. Margaret Price and Stephanie L. Kerschbaum outline the importance of centering disability from the beginning of a research project; they describe how centering disabled people's narratives as well as access remakes research as "One of our purposes in telling stories is to offer them as opportunities to reflect deeply on the beauty, complexity, and pain of research."[20] We come to find one another online, in support groups, through shared (and differing) experiences and identities, and we develop culture, languages, technologies, support systems, art, and other maker-cultures. Therefore researching disability comes with disabled people at the center and the unique ways in which we navigate the world and relate to one another.

Reflecting on our communities and countering the dominant narratives surrounding 'independence'—a myth whereby one can (and should) exist without the support of others—Disabled scholars have written about the *value of community* for disabled people. Leah Lakshmi Piepzna-Samarasinha, for one, highlights collective care systems, which help counteract how traditional medical systems of 'care' can be abusive, transphobic, homophobic, sexist, racist, and also financially unattainable. She describes queercrip scholar, Loree Erickson's care collective

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[17] Mia Mingus, "Access Intimacy, Interdependence and Disability Justice," *Leaving Evidence* (blog), April 12, 2017, https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/, emphasis hers.

[18] "Disability Inclusion Overview," World Bank, accessed September 8, 2019, https://www.worldbank.org/en/topic/disability.

[19] Mia Mingus, "Access Intimacy, Interdependence and Disability Justice," *Leaving Evidence* (blog), April 12, 2017, https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/.

[20] Margaret Price and Stephanie L. Kerschbaum, "Stories of Methodology: Interviewing Sideways, Crooked and Crip," *Canadian Journal of Disability Studies* 5, no. 3 (October 31, 2016): 18–56, https://doi.org/10.15353/cjds.v5i3.295.

where "disabled and non-disabled friends and community members… work shifts each week to help her with dressing, bathing, and transferring …. [as well as] the admin work of emailing, scheduling, and training potential care shifters."[21] She emphasizes that "Loree's care collective is not just a practical survival strategy to get her the care she needs; it's a site of community and political organizing, where many people learn about disability politics (both the theory and the nitty-gritty) in action for the first time."[22] Along such lines, Mia Mingus proposes the concept of 'interdependence', which "moves us away from knowing disability only through 'dependence,' which paints disabled bodies as being a burden to others, at the mercy of able-bodied people's benevolence." She critiques that "The myth of independence reflects such a deep level of privilege, especially in this rugged individualistic capitalist society and produced the very idea that we could even mildly conceive of our lives or our accomplishments as solely our own."[23] She emphasizes, "to be clear, I do not desire independence, as much of the disability rights movement rallies behind. I am not fighting for independence. I desire community and movements that are collectively interdependent."[24] Furthermore, she highlights the interconnectedness of people's lives, in general:

> "Someone made the clothes you're wearing now, your shoes, your car or the mass transit system you use; we don't grow all our own food and spices. We can't pretend that what

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[21] Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver: Arsenal Pulp Press, 2018), 45.

[22] Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver: Arsenal Pulp Press, 2018), 45.

[23] Mia Mingus, "Access Intimacy, Interdependence and Disability Justice," *Leaving Evidence* (blog), April 12, 2017, https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/.

[24] Mia Mingus, "Interdependency (Excerpts from Several Talks)," *Leaving Evidence* (blog), January 22, 2010, https://leavingevidence.wordpress.com/2010/01/22/interdependency-exerpts-from-several-talks/.

> happens in this country doesn't affect others, or that things like clean air and water don't bound us all together. We are dependent on each other, period."[25]

Especially as top-down systems to accessibility and care do not work for many disabled people—specifically disabled queer, trans, and people of color—interdependence highlights new forms of support and care for survival. Interdependence, Mingus illustrates, points towards how disabled people rely not only on medical, government and bureaucratic systems but also on each other and collective access.

This chapter brings together the aforementioned facets—how disabled people have a long history of being misrepresented in archival material, the ways in which some marginalized communities feel a sense of erasure in archival material, and how community is a vital aspect of many disabled people's lives—in order to investigate disabled people's relationships to their representation, misrepresentation or erasure in archives. This chapter aims to fill a gap in archival literature on marginalized identities—which has focused explicitly on race, ethnicity, sexuality, and gender—and uses similar ethnographic methods to Caswell et. al. in addressing archival erasure.[26] My guiding question is "how do disabled people relate to disabled people in history?" I look to disabled people's affective responses to disabled people in history—even in their absence—how they also relate to the archives that contain such materials, as well as how both archives and records on disability shape disabled people's experiences of themselves and their communities. Through an attention to the materials on disability as well as how archives

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[25] Mia Mingus, "Access Intimacy, Interdependence and Disability Justice," *Leaving Evidence* (blog), April 12, 2017, https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/.

[26] M. Caswell et al., "'To Be Able to Imagine Otherwise': Community Archives and the Importance of Representation" 38, no. 1 (December 1, 2016): 5–26, https://doi.org/10.1080/23257962.2016.1260445; Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (Spring/Summer 2016): 58.

impact their interpretations, this research draws out a central relationship of crip provenance: how living disabled people's experience of archives contextualizes records across time.

Findings

In this chapter I will highlight four dominant themes that emerged from the data. First, many disabled people described that although they were familiar with prominent stereotypes of disability, they still felt an inherent violence in witnessing themselves misrepresented or underrepresented in history. Second, considering such dominant tropes of disability, disabled archival users often expect to be erased in history; they remarked on an expected absence of subjectivity as well as a complete lack of records about disabled people. Yet, thirdly, many participants talked about how they brought a critical and political lens to both their misrepresentation and erasure in archival material. And, finally, using such critical lenses, they nonetheless felt excited to see disabled people in history, because, although they are often misrepresented or represented in partiality, such documentation has the potential to be activated as evidence of the ways in which disabled people have been—and continue to be—treated and misunderstood. All of these findings are twofold: throughout all four themes, participants remarked both on the *presence* of limited or problematic representations as well as the *absence* of documentation about disabled people in history. And they highlighted how both misrepresentation and erasure occur through the creation of records and their contents as well as through archives, archival processes and interventions.

Moreover, the archives with which interviewees worked varied greatly; some would be considered mainstream archives and special collections while others identified disability-specific collections or framed themselves as a disability-centered archives. Throughout the various types of archives, people with disabilities were represented in a variety of ways—participants

remarked that although some collections purported to have disability-centered collections, problematic, limited, or medical representation was still prevalent. In other words, the findings described below are not limited to mainstream archives. Additionally, participants described a wide variety of records: although many described problematic, violent, and limited representations of disabled people, other interviewees referenced literature, media, and cultural objects that didn't always depict disability in an explicit or problematic way.

Finding 1: Violence in Misrepresentation

One theme that emerged from the interviews was the prominent experience of witnessing stereotypical representation of disability—as pitiable, as dangerous, as a medical 'problem' to be eliminated—and the familiarity that disabled people have with these tropes. Many interviewees talked about being personally familiar with these forms of representation of disability and also witnessing them within the language used and visual representation within records. Interviewee, Dr. Therí A. Pickens, a Full Professor of English, spoke about how disability is perceived through archives and general discourse. She states, "We are products of our time. And so the scholars who embrace those ways of those epistemologies [that portray disability in a limited way] are embracing them because they make sense. There's too much in general discourse that allows for a pitiable stance [around disability] to make sense. I'm talking in these complicated ways about archival research and critical literature and even, you know, kind of thinking about popular discourse."[27]Considering the ways in which disability is commonly understood—as pitiable, as a deficit, etc.—Pickens identifies how that discourse is reflected within archives and records' interpretations and does little to help complicate historical representations of disability.

[27] Therí A. Pickens, interview by author, September 6, 2018.

Speaking both about archives and general discourse, Lili Siegel, a white queer disabled woman and recent law graduate, spoke about the toll of witnessing absences and reintroducing disability into conversations which had previously neglected it:

> We spent weeks talking about the archives of World War II and Nazism [in a class]…. And this was a feminism class and there was no disability! And of all the times to omit—you know, like even most disabled folks get that disability was a 'thing' with a Nazism. That's not *that* advanced, I thought. But at the same time I was really debating: I don't want to end up being the person to write this whole paper about disability and Nazism because it's going to break me. It's going to make me so upset and sad and just depressed. And I think I walked that line a lot where I would super dive into disability and then pull back and dive in and pull back and think in some ways I'm still like navigating that. But it's hard not to see the real absence of it in almost every space.[28]

Such dominant discourses, where disability is understood as a medical problem and as pitiable, are often reflected in archival material, which participants noted. Dr. Stefan Sunandan Honisch, a multiracial disabled scholar, educator and musician, expressed witnessing one frequent stereotype of blind pianists in photographs, "The trope was of a blind musician with eyes closed. And…. this idea of 'inner experience', sort of uncontaminated or unaffected by the messiness of the real world, this ability for a blind musician to seek inward inspiration." He states, "I had a very strong, almost emotional response to that photograph when I first saw it…. I had become aware of certain tropes in the representation of blind musicians. So part of me was guarded as a researcher in studying these materials and remaining alert to the manifestation of

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[28] Lilith Siegel, interview by author, August 23, 2018.

these tropes."[29] Cody Jackson, a disabled, gay graduate student who was researching 19th century conduct manuals, spoke about how such representations work towards the eradication of disability. He states, "honestly, I think it [the record] was about eradicating both [queerness and disability] because I think the conduct manuals are about maximizing productivity and maximizing normality because when we see conduct manuals, they're usually reproducing norms."[30] Along these lines, Megan Suggitt, a disabled, white undergraduate student who was researching a Canadian asylum for developmentally disabled children, states "There's the side that the records will perpetrate how disabled people are seen [in negative ways]… people could see Huronia Regional Centre as something that was very helpful in the sense that they, you know, they 'kept' people... versus like instilling them in the community."[31] Such stereotypical representations of disability—and other marginalized identities—were described as pervasive within many different archives in which interviewees worked.

Although many participants described being unsurprised by the stereotypical representations of disability in records, many spoke about how such representations were emotionally difficult to bear witness to. Disability rights activist and author Corbett OToole talked about looking at institutional records from a Californian asylum. She states:

> When I looked at the archives, I mean clearly they were all labeled as disabled, which is why they were easy to find because institutional[ized] people, right?... It was like every page was a new kind of horror, you know, as I would look through the records… I'd look

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[29] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[30] Cody Jackson, interview by author, July 5, 2018.

[31] Megan Suggitt, interview by author, July 6, 2018.

> to see what was there about the people and you know, that's when I realized how incredibly capricious it was that they were even institutionalized.[32]

Michelle Ganz, self-described as, "half-Indian, half-Polish, half-deaf, 100% archivist," similarly spoke about the impact of seeing the struggles of disabled people in history while looking at pension records relating to injured soldiers. She states:

> it was so dehumanizing, and I really felt for so many of these soldiers, because so many of them were incredibly young and then were permanently disabled…. And then couple that with their disability and the fact that there was no support whatsoever. It really caused some of these people to go into horrible depressions and all these other mental issues that come along with the isolation of disability. It's heartbreaking because especially when you're looking at people who are already in an area that was already economically depressed before the war happened and then after the war, they never recovered… and you know, horrible depressions and all these other mental issues that come along with the isolation of disability. It's heartbreaking.[33]

White, nonbinary disabled scholar, Jess Waggoner spoke about researching a disabled woman who encouraged other disabled people to divest from each other once they were rehabilitated:

> That felt like a really violent shoot of rehabilitation culture that I think we don't always think about. We think about, you know, polio and post-polio syndrome and all of the

[32] Corbett Joan OToole, interview by author, July 17, 2018.

[33] Michelle Ganz, interview by author, August 14, 2019.

> attendant violences that can happen to your body and your mind when you're being sort of forcibly rehabilitated. But we don't think about also the encouragement that you integrate back into able-bodied culture, and you don't create connections with other disabled folks…. And there are so few spaces that encourage us to have a culture and a community and a sociality now, so that, to see in some ways the roots of this, *it's hard*.[34]

Suggitt talked about the impact that witnessing the violences of the past had on her research. "It almost made me not want to go back after I looked at all the documents. I just couldn't physically do that to myself because I knew after talking to the survivors I had actual real history and then going there and seeing such a huge lack of information, 'I don't physically think I can do that again.'"[35] She continues, "I feel that it's just really awful. I couldn't imagine being—I'm really grateful for the support I have now as a disabled student—but I couldn't imagine being in the Heronian Regional Centre and having my life seen in such a black and white state, like not being a person. They don't have any autonomy and it's just awful." OToole echoes, "it's a particular kind of hard work spiritually to do: to witness institutional stuff, trauma and abuse."[36]

These quotes illustrate how disability often gets misrepresented through stereotypes and limited tropes of disabled people—as medical 'problems', villainized as dangerous, and to be rehabilitated or eliminated. And although disabled people may be familiar with these dominant forms of the representation of disability, participants still had an emotional response to

[34] Jess Waggoner, interview by author, August 16, 2018.

[35] Megan Suggitt, interview by author, July 6, 2018.

[36] Corbett Joan OToole, interview by author, July 17, 2018.

witnessing people with disabilities portrayed in problematic ways as well as seeing how we have been treated in the past.

Finding 2: Expected Erasure

Although participants expressed a familiarity with ways in which disabled people are misrepresented in records as well as described the violence in such harmful stereotypes, many also talked about how they expect to be erased in history (in archives and otherwise). Interviewees specified both the expected erasure of disabled subjectivity in records—as records about us are often made by people in power and neglect to capture disabled perspectives—as well as the expected absence of documentation of disability in history in general.

Through their description of the dominant forms of how disability is understood, interviewees often expect such tropes to be reflected in archives. OToole told me “it felt like disabled people are raised that we’re not important, that our history is not important because it wasn't.”[37] Siegel spoke about trying to find a mentor who shared her experiences:

> I did a search for ‘law professor and CP [cerebral palsy]’, in like every resource that I could think of, thinking that I could send this person an email. And [the results] came up with a lot of things about medical malpractice law…. People were writing more about how you could get money for your kid [with CP] than they were about the possibility of being disabled in academia…. So I think it's not quite an archive story, but I feel like it kind of is, because it's like ‘where do you fit in? What do you even ask for to find your people?’[38]

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[37] Corbett Joan OToole, interview by author, July 17, 2018.

[38] Lilith Siegel, interview by author, August 23, 2018.

This experience is also reflected within how disabled people expect to be erased within archival material. OToole continues, “To tell you the honest truth, I think that disabled people are so often erased that I almost don't notice anymore. Like, I notice it for a minute and you know, if it's particularly egregious I might write something about it. But in general it's so common.”[39] Pickens, citing W. E. B. Du Bois, also illustrates this sentiment, “our epistemology, as a disabled person, is that you are aware of your invisibility ... if you're going to look for another analog, ‘double consciousness’, of being a disabled person in the world… I think epistemologically absolutely: you expect a certain degree of erasure.” She remarked about conducting research, “ I look for ‘me’ I think in part because the scholarship I'm interested in is driven by interests that are both personal and professional, intellectual and emotional… but *I also am prepared to not find me*. It's great when I do, but it doesn't hurt if I don't.”[40]

Such impressions of erasure were palpable in how interviewees spoke of the ways in which disability is represented in partiality; they spoke about the absence of subjectivity—or the lack of agency—of disabled people in their representation in records. Pickens reflects, “I think living with a disability makes it so if you didn't know, you certainly find out that people are not interested in documenting things from the perspective of the disabled.”[41] Travis Chi Wing Lau, a gay, disabled, poet and scholar of color, talks through his experience looking at Edward Jenner’s medical books, which erase the subjectivity of the sick and disabled people he documented while

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[39] Corbett Joan OToole, interview by author, July 17, 2018.

[40] Therí A. Pickens, interview by author, September 6, 2018.

[41] Therí A. Pickens, interview by author, September 6, 2018.

researching smallpox. Lau described how many people were "described with such detail but often in terms that depersonalized and sort of de-individualized that person," and states:

> I wish I were surprised by him, *but I'm not*. But I think that's also me thinking from a queer studies perspective about the fact that so often when we try to feel our way through the archive, our encounters are with these forms of objectification specifically in the forms of medical records that have no desire to see the subject of it or to see a self or fullness. It's really about quite literally medical objectification. And I see it here and I go, 'sounds like another day in the history of marginalized and oppressed bodies.'[42]

Waggoner spoke about discourse in records surrounding disabled women that neglected to include their voices:

> There were also just a lot of materials around policing a disabled woman's sexuality and her gender. And there was kind of an emergent literature that was sort of like, 'maybe the cognitively, intellectually disabled woman isn't as much of a problem as we think.' It was really just as patronizing, in some ways. It was really bad. And so folks were really arguing about how much should we worry about the white, delinquent disabled woman.[43]

Lau reflected on how to "articulate the perverse absent-presence of disability all over, especially in the archive." He identifies the partiality of records, "Yet again, you get an invocation of a disabled body but entirely removed of its subjectivity and agency. To me it's extremely perverse, but also something we've seen time and time again that I think goes to show the vast extent to

[42] Travis Chi Wing Lau, interview by author, August 16, 2019.

[43] Jess Waggoner, interview by author, August 16, 2018.

which disability has been sort of invoked for all sorts of reasons other than for the wellbeing of disabled people."[44] And Blind historian, Alida Boorn spoke about the sparse description of a disabled person in a record, "for him, It's just, [the record described him as] 'here's this guy. He had rheumatic fever. He survived, he carried on and he was blind' and it, and basically that said, 'well, yeah, here he was blind and he did this work anyway.' And that's about it, period. I'm going, well 'that's not a lot.' To research disability in history often means finding mis- or under-representations of disability, as records are created by people in power, through the objectification and erasure of disabled people's lived experiences.

Participants not only spoke about the lack of disabled subjectivity in records but also remarked on the palpability of the absence of records about disability, in general. Siegel described her experience using archives as an undergraduate and noticing the lack of representation of disability. "I didn't start out that way [looking for disability while doing research in archives], but it's hard not to notice absence, and *it's hard not to feel absent*. I think particularly in that first project that was about the way that people formed their identities as women in college and the fact that that I wasn't even able to find disability in that and I was in college."[45] Pickens, describing working at the Huntington Library, says "We were like, 'listen, this isn't complete.' But I think the experience of disability does set you up to realize that there's a certain kind of, there are just sort of gaps there."[46] Ganz states:

> I would not be surprised if we found out down the line that there were records that talked about how disabled people were treated. Like at Lincoln Memorial [University], they had

[44] Travis Chi Wing Lau, interview by author, August 16, 2019.

[45] Lilith Siegel, interview by author, August 23, 2018.

[46] Therí A. Pickens, interview by author, September 6, 2018.

an orphanage in like 1890. It was predominantly a girl's home but none of the records talk about the race of the children or if they had any disabilities…. There *were* people there of different races and there were people there of other levels of ability and none of that is noted. There were visible gaps in the record. So, to me, what I feel like we're going to end up discovering is that there has been an excising of the sort of material because it [that history] is embarrassing. And that is a problem with all archives and there's just nothing we can do about it.[47]

Jackson echoes, “there are a lot of stories that have yet to be told,” when reflecting on the lack of records around disability and his desire to bring records kept in private collections to light.[48]

Boorn spoke about her experiences researching George E. Hyde, a disabled historian, “There isn't much in archives with him. Because of the times and because some people, they kind of dissed his research, until now it's been proven—you know, he was very spot on—but there just isn't much out there. He kept like notes in shoe boxes…. And right now we just have begun working with trying to retrieve online newspapers because *it's just not there*.”[49] Ganz states, “I was really distressed by the fact that there is nothing—I couldn't even find case studies on hard of hearing in archives. And I don't know if that's because hard of hearing is only barely considered a disability.”[50] OToole describes the impact of such erasure, “It's kind of all the feels about: How easy is it for us to get locked up? How we never get out, how people get locked up for all kinds of capricious reasons that have nothing to do with actual function or need. And that

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[47] Michelle Ganz, interview by author, August 14, 2019.

[48] Cody Jackson, interview by author, July 5, 2018.

[49] Alida Boorn, interview by author, August 7, 2019.

[50] Michelle Ganz, interview by author, August 14, 2019.

when bad shit happens or when we die, it's just we become—we remain—we become invisibilized."[51]

As this data indicates—while sometimes painful to witness—erasure in some form is often expected. Through the ways in which interviewees described experiencing dominant tropes of representation of disability and how it feels deprioritized and misunderstood in society, they also articulated how they came to expect and acutely perceive it. The very lack of records on disabled people, or records that document disability in complex ways, is a palpable part of the process.

Finding 3: Criticality of Misrepresentations & Erasure

Although misrepresentation and erasure are expected, many participants brought a critical lens to these pieces of the representations of disability history. First, when participants spoke about witnessing problematic or limited representations, they described how they could grapple with and *problematize the misrepresentation of disability in records*. Many interviews described how they complicated problematic representations of disability. Honisch, for example, continues to recount his experiences with tropes around blind musicians and how he complicates them:

> There were moments in certain photographs when I did feel a kind of connection that, it's not like it made me forget about the tropes and about the importance of maintaining a certain critical engagement… it wasn't simply that the tropes ceased to become important or that I was unable to engage on a human level with those photographs—because I

[51] Corbett Joan OToole, interview by author, July 17, 2018.

> always have the sense that I was dealing with something staged or artificial—but something more conflicted happened [for me]… as a disabled researcher.[52]

Waggoner identifies the common disconnect between medical history and what might constitute disability history as well as their critical lens to reframe such records. They ask:

> What kind of *framing with care* do we need to use in order to transform something from medical history to disability history? Because I've seen there are moments where I encounter something that called itself 'disability history' or archives and I'm like, 'this is just a medical archive.' It's clinical, it's diagnostic. It's not really leaving a lot of room for agency, but I think that the researcher could possibly transform this into a disability archive. But I'm troubled sometimes by—not the ambiguity. I'm fine with the ambiguity—I'm troubled by the sort of uncritical naming of something that still feels pretty medical to me as 'disability.'[53]

Similarly, Honisch reflects about the subtleties in records and the desire to complicate records, "That to me is precisely where the value lies because they do force that kind of deeper effort precisely because the discourses aren't immediately or obviously offensive or jarring." He continues:

> When that kind of discourse isn't obviously at work, then as researchers, we have to expand perhaps even more effort to sort of ask those critical questions like, what's going on here? Are there sort of forms of exclusion that work or aren't there dynamics of power

[52] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[53] Jess Waggoner, interview by author, August 16, 2018.

and privilege that need to be unpacked? And whose experiences are being validated, whose aren't? Which is all just really to say that I think that the value then in those more ambiguous records… may very well lie in the extra sort of effort and the more subtle critical work that they perhaps ask us to do or perhaps even demand that we do.[54]

Others described how they grappled with partial or incomplete narratives**.** OToole states that, "What I came away with is that *we're there*; a lot of times disabled people are between the lines or are in situations we don't wish they were, in like institutionalized situations. But we're there and there's a lot of information about us and what, to me, what the challenge has been [is] how to take that information and make it useful and available to other people in a contemporary context."[55] And Jackson describes how "it's a bit of an emotional kind of laborious process because I tried to take a look at young gay men who committed suicide. And so I take a look at those kind of unfinished narratives and I try to figure out if there's an ethical way that we could entangle ourselves in those archival moments."[56]

Grappling with the partiality of the documentation around the deaths of disabled people after an earthquake at Agnews Developmental Center, a Californian psychiatric and medical facility, OToole states, "the historical record was there, but the fact that this history is completely ignored in the earthquake history is that kind of classic, 'incarcerated people don't get to be part of our mainstream history.'"[57] Such histories aren't always readily apparent in records, so participants, as Pickens points to, often look for the subtleties, "I was looking at these kinds of

[54] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[55] Corbett Joan OToole, interview by author, July 17, 2018.

[56] Cody Jackson, interview by author, July 5, 2018.

[57] Corbett Joan OToole, interview by author, July 17, 2018.

moments where things pop up into popular discourse and in open conversation. I think each of those has that in common: where the body's fragility allows disability to be called by other names and allows for people to think with a little bit more granularity about the experiences of disabilities, sometimes without ever naming it as such." She continues about doing the work of locating disability, remarking on the lack of critical frameworks to address race and disability:

> I found some places where disability was not heralded as, not called as such, where it was talked about in terms of blood, cause that's how pseudoscience wanted to talk about in the 19th century. And so scholars working on the 19th century used that terminology—I believe historians call it 'source bleed'—so that was fascinating to find. What was also fascinating was that there were all of these folks itching to talk about disability and trying not to do so from the standpoint of pity, but they didn't quite have the vocabulary to describe how pervasive the experience was… I think that's also the absence of something that is uniquely Black, about the experiences of blackness and disability. So the critical armature, even if it existed for some people, it's too white.[58]

Through encountering the partiality of records around disability and interpretations of them—whether from the representation stereotypes, the absence of perspectives of disabled people, or the lack of complex ways to address how race, gender, class, size and nationality inform how disability is understood—interviewees described their critical engagements with records. These quotes illustrate how interviewees critically approached stereotypical representations of disability in history as well as how records can be incomplete.

[58] Therí A. Pickens, interview by author, September 6, 2018.

Moreover, participants not only talked about being critical of stereotypes, tropes and such limited perspectives of disability in the historical record, but also spoke about taking a *critical lens towards the absence of records about disability*. Pickens spoke about training a critical lens on the nuances of erasure stating, “Sometimes I think the integrity of talking about disability, whether it's present in the archival record officially or not, requires saying something about what kind of erasure we're dealing with. Like whether it's a deliberate erasure by the people or persons who left things behind or whether it's erasure based on our archival methods or whether it's an erasure because people didn't know or didn't have a critical vocabulary.”[59] Lau, reflecting on the six people forcibly vaccinated in Newgate Prison, reflects on identifying records never created about disabled people:

> I think about those unnamed bodies, those unnamed *criminal* bodies. And there's really no specific case details about who those people were, but I wouldn't be surprised if there were women or people of color, as the sort of experimental matter by which a practice became popularized and justified to the English elite. So when I saw this, I just thought [this is] another extension of that yet again, certain bodies being useful insofar as they can be objectified and committed to medical knowledge and then made okay for other people to reproduce that knowledge. What do we do with the fact that disabled people frequently are the very matter by which medical knowledge advances? That was my first instinct was to say ‘what do we do with that?’”[60]

[59] Therí A. Pickens, interview by author, September 6, 2018.

[60] Travis Chi Wing Lau, interview by author, August 16, 2019.

Expanding on archival work, Lau states how "you would often have to extrapolate sort of the number of bodies not represented, how the data itself is a distortion of what was a much larger phenomenon. So yes, it's been weird just sort of toggle between the individual experience of, say, a person whose smallpox case was ideal for vaccination and this population-level record in which thousands of bodies are being conflated into a single piece of evidence that justifies the use of vaccination."[61] Considering how identifying and addressing the partiality of disability histories is often painful and arduous, many interviewees described how they applied a critical lens to the lack of complex representations and ways to engage with them.

This finding outlines the critical ways in which disabled people described their interpretations of disability in records: interviewees described how they complicate problematic or stereotypical representations of disability, how they recognize when narratives are incomplete, and how they also detect the palpable absence of disabled people in archives. Such strategies included engaging with tropes to locate forms of agency, developing critical vocabularies for talking about disability in history, and recognizing when disabled people are "between the lines" or histories need to be extrapolated from sparse documentation.

Finding 4: Affective Impacts & Political Potential

The previous three findings—the stereotypes we're used to, the ways in which we expect to be erased, and the ways in which we critically read the partial nature of disability in records—point to a notable complexity around representation, misrepresentation, and erasure in history. As such, participants described a particular tension: between witnessing problematic

[61] Travis Chi Wing Lau, interview by author, August 16, 2019.

representations and glaring absences, and being able to foreground how those violences or inaccuracies can also be seen as evidence of our histories.

Interviewees described how such representations, although often inaccurate to the lived experience of disabled people, could still serve as evidence of past violences, which, with a political lens, could therefore be activated to tell the history of violences against disabled people. Pickens talked about the complexity between the absences within a record and their potential, again drawing on Du Bois's concept of 'double consciousness,' where we are "always looking at one's self through the eyes of others."[62] She states, "To encounter it [a Black disabled woman in archives] is I think to feel this strange mix of *being seen and unseen* because you're cognizant of what's on the [record], what you see in front of you, what you're touching: literal evidence."[63] Boorn articulates that even when one finds a small hint of disability in records, "It feels good. It says 'if you're persistent, keep going.'"[64] And Suggitt conveys an importance of the Huronia Centre's records, "I feel like people need to be aware of this history. And the thing with disability history is people are erased, disabled lives are erased and [addressing the history] is not done in a meaningful manner. Like you need to actually acknowledge what happened. It is history. You need to maintain that history so people are aware that this happened."[65] Lau similarly posits the use of a better understanding of gaining historical context of the ways in which disabled people have been and still are treated: "especially thinking about the history of incarceration and institutionalization of disabled people, it, on a very simple level, makes us all have to say that this is not a recent thing. This is very far back in history…. I think about how

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[62] William Edward Burghardt Du Bois, *The Souls of Black Folk* (Courier Corporation, 1994), 8.

[63] Therí A. Pickens, interview by author, September 6, 2018.

[64] Alida Boorn, interview by author, August 7, 2019.

[65] Megan Suggitt, interview by author, July 6, 2018.

often these discussions get restricted to the 19th century or later. But you can clearly see the underpinnings of this in the [18th century] period, what we would think of as before medicalization happen."[66] Ganz also addresses how records have the potential to tell crucial pieces of history: "there's a lot of people who want to go back and change records to update them to less hurtful language. And for me that goes against everything we're supposed to be doing because it's changing the truth, and the truth may be hurtful, but we need to acknowledge it in order to move forward."[67] Likewise Honisch spoke of the political possibilities of historical material: "I think that raising those questions in terms of societal and cultural attitudes as a whole, that's a valid and perhaps an important critical undertaking. So then the balance of going back to these photographs becomes sort of dance almost between unpacking or trying to get at the political possibilities for example, and the sort of potential disruptions that a certain way of reading those photographs might bring about."[68] Such quotes begin to demonstrate a connection that disabled people feel to those in the past; utilizing records can illuminate crucial pieces of disability history.

Witnessing these records had a personal effect on not only how some interviewees understood disability history but also their personal identity and relation to that history. Jackson reflects broadly on disabled people represented in historical records and his relation to them: "particularly with archives, I think it just kind of reminds me that there were disability activists before me doing this work. And I have ancestors and people in the past that I can look to who have done this work and put their bodies on the line."[69] And Siegel reflected on how archival

[66] Travis Chi Wing Lau, interview by author, August 16, 2019.

[67] Michelle Ganz, interview by author, August 14, 2019.

[68] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[69] Cody Jackson, interview by author, July 5, 2018.

material has facilitated a shift in her personal and political understanding of disability and discrimination:

> "I think that when I first learned about the disability rights movement and the ways in which it sprang out of a history of eugenics…. it has a weight that I hadn't ever thought of it with, where I felt like I got why people were so upset, for the first time. I hadn't really let myself feel much by way of like anger. And my thing about people who didn't get disability was just like 'oh well, they don't know better but it's not me, they don't hate me, they don't think I'm disgusting'. And then I learned about the history more, and it was like, 'wow, maybe they do hate me,'.... It was good that I grappled with some of that, but it also really is painful."[70]

Witnessing disabled people in the past, and the activism, discrimination and mistreatment that they went through, allowed for participants to feel connected to disability history.

Along these lines, many spoke about the affective duality of the painful nature of witnessing violences of the past, while also feeling excitement to witness disabled people—even though problematically represented—in history. Waggoner talked about finding illustrations that disabled women produced for promotional materials for a rehabilitation center. They describe feeling connected to people in the past:

> "There is this excitement of *we were here* like, *absolutely*. And that we took up space…. I'm just sort of was blown away in terms of like… this gorgeous documentation of these women being here and these women performing this labor...for pennies. and yet it's so insidious. I'm excited that the document exists and that it's rendered in this very

[70] Lilith Siegel, interview by author, August 23, 2018

aesthetically pleasing way--you're not usually encountering a ton of like disability art, visual art, in the early 20th century, at least in this particular way--And so that was really exciting. And to see those and be drawn to them in that way. But then to also be like, 'this is part of an advertisement,' that you should send your 'problem girl' here, police or parents or families or whatever… so definitely complicated around that. Excited to see it, *excited that it's there in an archive, but felt really weird about it*."

Boorn describes a personal connection to archival material and excitement while doing researching early sunglass production: "I was going blind and [researching] sunglasses.... finding it from the archives, it was a very exciting because I was getting to tell the story using the advertisements in the newspapers."[71] Honisch describes the excitement of getting to see disabled people in history, expanding how:

> "Misrepresentation isn't simply a straightforward opposition between invalidating disabled people's lived experience and sort of representing them according to stereotypes. There is also that satisfaction or *that 'aha moment' that comes from seeing other disabled people historically present*… I feel like a similar kind of complexity was in my response to that photograph [of a blind pianist] in particular where… despite recognizing that it wasn't simply the case that I thought to myself, 'here's another photograph participating in a in a worn out old trope,' it was more complicated 0than that."[72]

[71] Alida Boorn, interview by author, August 7, 2019.

[72] Stefan Sunandan Honisch, interview by author, July 18, 2018.

He continues, “So there can be that sort of sense of alienation or frustration of being led in a problematic discourse or sort of having to engage with a problematic discourse. But coupled with that recognition, there's something nonetheless significant about the fact of inclusion.” Lau similarly spoke about the complexity of wanting to see disabled people in history even though they are often problematically represented. He states, “It's a desire I sometimes don't know what to do with because I feel its problematic nature.” And Pickens likewise articulates the emotional complexity she feels when performing archival research:

> “This [experience of looking for disability] was sort of enmeshed in something that I think violates the laws of physics. I was in like six different places at the same time. You know what I mean? Like it felt like this confluence of emotions; this anger, this fear, this excitement, this beauty, this difficulty, and then this sort of hope. If someone would but understand this piece of paper and this archive and its importance, then maybe I won't have to fight these battles anymore… *It felt like everything*.”[73]

OToole states that:

> “[even when looking at these horrors] what I came away feeling like was *I was really grateful that the public record existed* like the basic public record so that other people could find what I found… and I was grateful for the absolute bean-picking bureaucracy of everybody who goes in and has to get registered so we know some basic information, some self reported basic information about these people. So that part felt really good. I mean, I really felt like having that information in the record was really important to me

[73] Therí A. Pickens, interview by author, September 6, 2018.

because *I felt like there were ways in which I could connect with them*. That felt really relevant."[74]

Due to the ways in which disabled people expect to be erased in history, through often problematic or limited representations of disability in records, this finding illustrates an inherent excitement in seeing yourself in history. Through such representations, participants not only felt a deep connection with histories of institutionalization, incarceration, and discrimination, but also understood these records as having the potential to be activated as evidence of the ways in which disability is perceived and understood.

Discussion

These findings build towards illustrating the complex ways in which disabled people find, relate to and are impacted by archival representation, misrepresentation and erasure. (1) As disability is often understood and portrayed through stereotypes, participants described that although they were familiar with prominent tropes and misrepresentations of disability, they still feel an inherent violence in witnessing the objectification of disabled people in the past. (2) Participants not only had a familiarity with how they are represented in stereotypical ways, but also often expected to be erased—through the frequent lack of subjectivity in records about disabled people and the lack of records in general around disability. Yet, (3) they approach archival material with contemporary critical lenses towards problematic representations and absences in order to (4) frame such representations as evidence of the ways in which disability is perceived and understood and therefore value connecting to disabled people across time.

[74] Corbett Joan OToole, interview by author, July 17, 2018.

In a way, interviewees expressed a similar affective impact to Caswell et. al.'s description of archival symbolic annihilation, where they feel represented in problematic ways and also feel erased in history. Disabled people are so deeply familiar with the ways in which they are misunderstood in society—through stereotypes and tropes—and witness how that is reflected in archives. They therefore can feel an inherent, or familiar violence around the ways in which disabled people have been (and continue to be) treated as well as how it is reflected within records and the ways in which disabled people are documented. Nonetheless, because we expect to be erased—either through the partiality of records created about us or the lack of records entirely—when we see ourselves in history, the affective impacts are complex. In thinking about symbolic annihilation alongside the dominant forms of representation of disability in history—such as institutional, criminal, and freak show records—there is a strong sense of anticipated layers of erasure. The expectation that we will not see ourselves in history, or at least will not see ourselves characterized in complex ways, feels to be a crucial piece to disabled people's relations to their representation. When one doesn't often get to see themselves in history and acutely perceives what Lau names as the "perverse absent-presence of disability," we consider, as Jackson describes, the multifaceted ways in which "we could entangle ourselves in those archival moments." We can "[come] away feeling… really grateful that the public record existed," as OToole states, an "excitement of *we were here*," as Waggoner describes, and an avenue to, as Suggitt and Ganz point at, "to acknowledge what happened." And, as Pickens tells us, "If someone would but understand this piece of paper and this archive and its importance, then maybe I won't have to fight these battles anymore." In one way, the counteracting of the expected erasure initiates an excitement and connection with disabled people in history. And, on the other hand, those records serve as evidence of the oppression and objectification of disabled

people which participants understand as having "political possibilities," as Honisch states, where "the researcher could possibly transform this into a disability archive," as Waggoneer notes.

These findings illustrate how disabled people have a unique relationship to archival representation, misrepresentation and erasure, around which I utilize Lau's words to propose the term *perverse absent-presence*. This term places focus on two aspects of disabled people's relationships to archival representation. First, it highlights the dual nature of problematic representation and erasure for disabled people: to feel, as Pickens states, a "confluence of emotions; this anger, this fear, this excitement, this beauty, this difficulty, and then this sort of hope." Whereas Caswell et. al. describe those marginalized by mainstream archives as essentially feeling erased in history through the ways in which they are misrepresented or underrepresented in mainstream archives, participants in this research, as Honisch describes, didn't feel "simply a straightforward opposition." They could simultaneously feel the harm of the treatment of disabled people—as well as their misrepresentation and erasure in records—*alongside* a complicated excitement or gratitude for evidence. As "an invocation of a disabled body… entirely removed of its subjectivity and agency… is extremely perverse, but [is] also something we've seen time and time again," we can understand partial, problematic, violent, ineffective, completely absent representations of disability in political ways. Lau's words draw on Halberstam's concept of "perverse presentism," which acknowledges temporal differences—to be cautious of superimposing contemporary configurations of identity on to the past. Halberstams's concept is "not only a denaturalization of the present it also an application of what we do not know in the present to what we cannot know about the past," which also applies to this data[75] Therefore this aspect of perverse absent-presences—the ways in which disabled people not

[75] Jack Halberstam, *Female Masculinity* (Duke University Press, 2019), 53.

only experience the harm of the past but also feel deep attachments to and appreciation for seeing themselves in history because such records can serve as evidence of our oppression—complicates archival symbolic annihilation: in one sense inaccurate or partial representation is harmful, yet, in another, the history of documentation and misrepresentation of disabled people *is illustrative* of how we have been treated across time and understood by people in power. Therefore the critical lenses that disabled people bring to partial or harmful records can activate them to tell parts of our histories. The very records that advocate for the eradication or institutionalization of disability can also serve as evidence to be politicized for our contemporary liberation.

Second, the relationships created through such perverse absent-presences of disabled people in records, points to the *necessity* for disabled people to see themselves in history, to relate and be in community with—as Jackson puts it—our ancestors, those "who have done this work and put their bodies on the line," even if represented in limited or painful ways. OToole describes feeling grateful, how "there were ways in which I could connect with them [disabled people in the past]." Waggoner illustrates how, although problematic, they nonetheless felt the value that "*we were here*." And Honisch described the "satisfaction or that 'aha moment' that comes from seeing other disabled people historically present." As these quotes illustrate, many interviewees felt a sense of connection with disabled subjects of records. The ways in which they witnessed disabled people across time evoked a sense of excitement to be able to see pieces of their identity in records. And, against the ways in which disabled people are hard to find in records, being able to witness disability in archives created a sense of connection with disabled people across time, highlighting the value and importance of witnessing disabled people in history

Mingus describes the ways in which disabled people feel connected to one another through the term "interdependence." She states, "Interdependency is both 'you and I' and 'we.' It is solidarity, in the best sense of the word. It is inscribing community on our skin over and over and over again. It is truly moving together in an oppressive world towards liberation and refusing to let the personal be a scapegoat for the political."[76] Through their excitement around and desire for evidence of disabled people, many participants expressed their communion with disabled people in the past, through their limited and problematic representation and even in their absence. Through the ways in which, as OToole states, "we become—we remain—we become invisibilized," disabled people can identify the traces of us in history, because, as Mingus writes, "the truth is: we need each other. We need each other. And every time we turn away from each other, we turn away from ourselves. We know this. Let us not go around, but instead, courageously through."[77] Similarly, this research demonstrates how disabled people feel connected to and in community to disabled represented in records.

Extending Mingus' term, I recognize that this research connects disabled people in community not only in the present moment, but also across time. Thinking about the history of sick and disabled people of the past, Piepzna-Samarasinha states, "Disability justice allowed me to understand that me writing from my sickbed wasn't being weak or uncool or not a real writer but a *time-honored crip creative practice*."[78] Likewise, records serve as evidence of disabled existence throughout time. The deep connection that interviewees felt to disabled people

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[76] Mia Mingus, "Interdependency (Excerpts from Several Talks)," *Leaving Evidence* (blog), January 22, 2010, https://leavingevidence.wordpress.com/2010/01/22/interdependency-exerpts-from-several-talks/.

[77] Mia Mingus, "Interdependency (Excerpts from Several Talks)," *Leaving Evidence* (blog), January 22, 2010, https://leavingevidence.wordpress.com/2010/01/22/interdependency-exerpts-from-several-talks/.

[78] Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver: Arsenal Pulp Press, 2018), 17, emphasis mine.

represented in records underscores an *interdependence* not only with current communities but also with disabled people in the past. Thus this research underscores Mingus's concept of interdependence to highlight the *expansive temporal nature of interdependence*: disabled people feel in community with those in the past, describing not only a sense identity through records—experiencing the importance of how "we were there"—but also feeling in community with them—to have ancestors and to feel connected to them.

Furthermore, considering the multiple and expansive temporal aspects of both archives and disability an *archival interdependence* not only points backwards, to our histories of oppression, resistance and resilience, but also forward, towards our collective liberation. Piepzna-Samarasinha writes, "I passionately believe in recording sick and disabled QTBIPOC [Queer, Trans, Black, Indigenous, People of Color] stories, and because I believe the stories I have witnessed and participated in over the past decade of building ways of creating care both a core part of disability justice work and the work of making the next world, the world we want."[79] Along these lines, interviewees described how they could activate records to retell histories and, as OToole described "how to take that information and make it useful and available to other people in a contemporary context," so, as Suggitt emphasizes "people are aware that this happened." Within their critical approaches to the past were also imaginings of the future—where people could be aware of disability histories, learn about the nuances around disability, and could therefore better understand disabled people in the present and into the future. The perverse absent-presence of disability in archives, then, describes not only multifaceted affective responses to the representation of disabled people in the past, but also the need for, commitment to, and interdependency with disabled people across time and towards a more just future.

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[79] Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver: Arsenal Pulp Press, 2018), 35..

Disabled communities, as this data shows, are connected not only through cross-disability solidarity, but also across time and space—through learning about past oppressions, struggles, activism, resilience, and existence of disabled people, even through their absence in historical records. This research demonstrates the necessity for disabled people to see themselves in history and underscores how disabled people can feel a deep sense of community not only with current communities—which is so vital to our existence—but also with disabled people across time, thus illustrating an archival interdependence.

Conclusion

By proposing the terms *perverse absent-presence* and *archival interdependence*, this chapter has shown how the representation of disability is frequently perceived as having limits, whether intentional—through how records were created for the containment and criminalization of disabled people—unintentional through documentation practices around medical history and disability, or through archival decision-making—their description, and placement in archives. Because of the ways in which disability is frequently simplified, misunderstood, objectified, and stereotyped, erasure is often a central piece to the disabled experience. Disabled people recognize those levels of erasure as pervasive and inherent to the disabled experience, therefore the ways in which it's reflected in archives is meaningful. Through shedding light on the interdependence of disabled people with our histories, this research solicits much future investigation. For example, through understanding disabled people's complex relationships with their misrepresentation in archival material, might archivists be less likely to intervene or 'correct' harmful or problematic descriptive language? Interdependence, as many note, is not just collective care between disabled people, but expands broadly to include the non-disabled people supporting disabled people. Therefore, I ask, how might archivists work with disabled

communities to further foster interdependence and forge new solidarities with multiple archival subjects, users, creators, donors, and communities?

This chapter shows how a crip provenance lens draws attention to *people*—not only creators, subjects, and archivists but also the people who experience, interpret, and are impacted by records across time. This research, by illustrating the ways in which disabled people use and are affectively impacted by and feel in community with archival materials, demonstrates a fundamental aspect for the following chapters of this dissertation to build upon. By centering the needs of disabled people to see themselves more complexly represented as well as the complicated ways in which they relate to misrepresentation and to erasure, I aim to show the deep affective connections of living disabled people to each other[80] through this research—as a diverse community with multiple intersecting identities, politics, and opinions—as well as to disabled people across time. Through an attention to the materials on disability as well as how archives impact their interpretations, this research draws out a central relationship of crip provenance: how living disabled people's experience of archives contextualizes records across time. The unique lenses that disabled people bring to archives—to locate, interpret, complicate, and affectively experience records on disability—create a constellation of contexts for how we understand disabled people in history.

Thus, this chapter not only illustrates the archival ways in which disabled people are in community with one another, but also lays the foundation to better understand the nuances of archival erasure as well as the need for a *political activation of archival material* through the development of robust critical and theoretical frameworks for archivists and archival users alike.

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[80] After all 10 interviews were complete, I emailed each participant to get their consent to connect them as a cohort. Currently, 8 out of 10 participants have been connected with one another via email, and all participants will have a chance to read and edit any work I produce from the interviews before it is published.

By centering *archival interdependence* in response to these findings, the chapters that follow will echo such expansive, political, and interdependent relationships created through archives, records, values, and disabled people throughout time. In building towards a crip provenance—where instead of solely focusing on the history of a fonds, we focus on all of the new connections that can be made through disability and archives—starting with the *people* who are impacted by representations of disability, interpret records and histories in unique ways, and are invested in more just futures is just the beginning.

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Chapter Four: Systems
Archival assemblages: applying disability studies' political/relational model to archival description[1]

Introduction

Sitting at a large wooden table in the reading room at the Harold Washington Library Special Collections, I begrudgingly open a folder named, "The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892),"[2] while looking for records about disability. As I read through the circular—which produced for the Department of Moral and Social Reform as part of the WCE—I feel the familiar sting of reading the words "delinquents", "criminal", "insane", "feeble-minded", and "pauperism" in the record, each part of different events happening over the seven days of the World's Congress Auxiliary meetings. I think how words such as "insane", "feeble-minded", and "pauperism" have been associated with and used against my disabled community, implying that we are lesser than others and how efforts of "reform" for "criminals", "the insane", and other "delinquents" were interwoven systems that villainize disabled people, people of color, poor people, and others who do not appear to uphold certain "moral and social" standards. Those words, for me, draw in all of those who participated in and were (and still are) affected by the creation of such records that were established around ableist, racist, and classist ideals. Yet, *the description of this record* in the Chicago Public Library online finding aid—within the 2.5 linear feet of World's Congress Auxiliary material—

[1] Substantial portions of this chapter were previously published in Archival Science: Gracen Brilmyer, "Archival Assemblages: Applying Disability Studies' Political/Relational Model to Archival Description," *Archival Science* 18, no. 2 (June 1, 2018): 95–118, https://doi.org/10.1007/s10502-018-9287-6.

[2] "The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892)," World's Congress Auxiliary Pre-Publications, Programs and Circulars Collection (Department of Moral and Social Reform, 1893 1889), Box 3 Folder 58, Chicago Public Library, https://www.chipublib.org/fa-worlds-congress-auxiliary-pre-publications-programs-and-circulars-collection/.

is limited to “The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892).” This record is a palpable example of how complex histories are underrepresented within archival description.

So far, this dissertation has looked to the disabled people who experience archival representation as part of what contextualizes records, the beginning of working towards a crip provenance. The previous chapter showed how the people who experience records and the archivists that process them are part of a crip provenance as they add context, affect, and politics. In response to Chapter Three’s illustration of the need for a political activation of archival material, this chapter takes a theoretical turn to archival material and builds a critical lens around *systems and language* as a way for archivists and archival users to complicate records' description through a crip provenance. Specifically, it investigates how the multiplicity of people, places, politics, and materials can be illuminated through a new disability studies theoretical lens and represented within archival description. My affective response—as a disabled person and an archivist—is an instance embedded in an *archival assemblage*—the complex personal, material, political, and collective histories and systems in which this record is located—that produced and continues to (re)produce that record. I yearn for this record not simply to be condensed and described as part of the “Department of Moral and Social Reform, The International Congress of Charities, Correction and Philanthropy” as it is in the online finding aid—but also to demonstrate its political and relational attachments, the multiplicities of which digital tools can afford to show. A connection to the history of systems of oppression feels necessary to contextualize the potency of this record, to offer more to archival users to understand the history of this record. I am left wondering if other users will understand this record as nestled within a larger body politic and within interlocking systems. I am left

wondering about the decisions made by the person(s) who created the record, who appraised it as worth being a part of an archives, and why it was selected for processing for the online catalog, as the lack of transparency within the record as well as in its description is noticeable. I am left wanting more.

Disability studies provides critical models that recognize history, conceptualize systems of oppression, and can expand the ways in which records are produced, processed, and understood. In particular, an application of the political/relational model of disability studies to archival description first highlights an intersectional approach to *systems of power and oppression*. Second, this approach proposes understanding descriptive language within the framework of *assemblage theory*. This chapter aims to build theory to illuminate the political possibilities of archival description as part of crip provenance. I will first expand upon understandings of archival power by describing the framework of a political/relational model of disability and the ways in which it builds off of or contrasts with the social and medical models. Then I will utilize the political/relational model to uncover how archival processes uphold systems of power and authority within archives. Through this application, I will examine two archival stages, records creation and description, to demonstrate that an assemblage-like approach to archives is crucial for politicizing archival material and can offer a nuanced starting point for contending with records description today. This chapter builds theory around archival description and shows how a crip provenance can highlight not only the systems that produced a single record or fonds, but also all of the interlocking systems that created and influenced the creation of other records, entangled with legislation, archival processes, attitudes, language, and records across time. By not solely orienting backwards nor aiming to reconstruct a 'complete'

provenance, this lens facilitates destabilizing self-evident categories and connecting seemingly disparate sources as a part of an assemblage to expand description.

Why Feminist Disability Studies for Archival Description?

Over the past fifteen years, a shift has occurred within archival studies. Archivists, traditionally depicted as neutral custodians of records, are now acknowledged as active participants in records who shape and are shaped by history.[3] Recent scholarship has challenged traditional ideals of neutrality within archives[4] and has emphasized how value is embedded in archival processes through the assumption that certain records have value for future use.[5] Sue McKemmish, Shannon Faulkhead and Lynette Russell, for example, have challenged the bias engrained in colonialist description and identified a need for co-constructing the description and appraisal practices with Indigenous communities.[6] Notably, many archival scholars have expanded these concepts by incorporating critical theory, such as feminist epistemologies, queer theory, indigenous epistemologies, and critical race studies to contest normative frameworks

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[3] Terry Cook and Joan M. Schwartz, "Archives, Records, and Power: From (Postmodern) Theory to (Archival) Performance," *Archival Science* 2, no. 3–4 (2002): 171–85, https://doi.org/10.1007/BF02435620; Ricardo L. Punzalan and Michelle Caswell, "Critical Directions for Archival Approaches to Social Justice," *The Library Quarterly* 86, no. 1 (December 21, 2015): 25–42, https://doi.org/10.1086/684145.

[4] Anne Gilliland, "Neutrality, Social Justice and the Obligations of Archival Education and Educators in the Twenty-First Century," *Archival Science* 11, no. 3–4 (November 1, 2011): 193–209, https://doi.org/10.1007/s10502-011-9147-0; Verne Harris, "Postmodernism and Archival Appraisal: Seven Theses," *S. A. Archives Journal* 40 (June 1998): 48.

[5] Brien Brothman, "The Past That Archives Keep: Memory, History, and the Preservation of Archival Records," *Archivaria* 51, no. 0 (January 1, 2001): 48–80; Tom Nesmith, "Seeing Archives: Postmodernism and the Changing Intellectual Place of Archives," *The American Archivist* 65, no. 1 (January 1, 2002): 24–41, https://doi.org/10.17723/aarc.65.1.rr48450509r0712u; Joan M. Schwartz and Terry Cook, "Archives, Records, and Power: The Making of Modern Memory," *Archival Science* 2, no. 1–2 (March 1, 2002): 1–19, https://doi.org/10.1007/BF02435628; Ciaran Trace, "On or Off the Record? Notions of Value in the Archive," in *Currents of Archival Thinking* (Santa Barbara, Calif.: Libraries Unlimited, 2010), 47–68.

[6] Sue McKemmish, Shannon Faulkhead, and Lynette Russell, "Distrust in the Archive: Reconciling Records," *Archival Science* 11, no. 3 (November 1, 2011): 211–39, https://doi.org/10.1007/s10502-011-9153-2.

within archives.[7] These works are situated in a vast body of scholarship that has uncovered the notion that there are constructions of value, by certain people and for certain people, within all archival facets.

Disability studies, interinformed with other critical theory, conceptualizes the ways in which disability is irreducible to bodily and mental difference. The field highlights how disability is produced, understood in society, and responded to in cultural, environmental and material ways. As Kim Q. Hall notes, "[b]uilding on [previous models] of disability... and feminist theory's analysis of the naturalization of both sex and gender, [feminist disability studies] can suggest an avenue for critique of reductive biological understandings of both gender and disability."[8] Feminist disability studies transforms feminist theory and disability studies by exploring how race, class, gender, sexuality, age and ability are identified in relation to each other and in comparison to a white, able-bodied, male "norm". Mia Mingus urges that, "[a]bleism must be included in our analysis of oppression… Ableism cuts across all of our movements because ableism dictates how bodies should function against a mythical norm—an

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[7] For example see: Melissa Adler, *Cruising the Library: Perversities in the Organization of Knowledge*, 1 edition (New York: Fordham University Press, 2017); Michelle Caswell and Marika Cifor, "From Human Rights to Feminist Ethics: Radical Empathy in the Archives," *Archivaria* 82, no. 0 (May 6, 2016): 23–43; Michelle Caswell, Ricardo Punzalan, and T.-Kay Sangwand, "Critical Archival Studies: An Introduction," *Journal of Critical Library and Information Studies* 1, no. 2 (June 27, 2017), https://doi.org/10.24242/jclis.v1i2.50; Emily Drabinski, "Queering the Catalog: Queer Theory and the Politics of Correction," *The Library Quarterly: Information, Community, Policy* 83, no. 2 (2013): 94–111, https://doi.org/10.1086/669547; Anthony W. Dunbar, "Introducing Critical Race Theory to Archival Discourse: Getting the Conversation Started," *Archival Science* 6, no. 1 (March 1, 2006): 109–29, https://doi.org/10.1007/s10502-006-9022-6; Jamie A. Lee, "Be/Longing in the Archival Body: Eros and the 'Endearing' Value of Material Lives," *Archival Science* 16, no. 1 (March 2016): 33–51, https://doi.org/10.1007/s10502-016-9264-x; María Montenegro, "Subverting the Universality of Metadata Standards," *Journal of Documentation*, July 8, 2019, https://doi.org/10.1108/JD-08-2018-0124; Hope Olson, "Patriarchal Structures of Subject Access and Subversive Techniques for Change," *The Canadian Journal of Information and Library Science* 26, no. 2/3 (2001): 1–29; Tonia Sutherland, "Archival Amnesty: In Search of Black American Transitional and Restorative Justice | Journal of Critical Library and Information Studies," *Journal of Critical Library and Information Studies* 1, no. 2 (June 2017), https://journals.litwinbooks.com//index.php/jclis/article/view/42.

[8] Kim Q. Hall, ed., *Feminist Disability Studies* (Bloomington: Indiana University Press, 2011), 5.

able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability."[9]

This approach acknowledges how systemic ableism, racism, classism, sexism, and homophobia are also inter-informed. Disability Justice activist Patty Berne states that "[w]e cannot comprehend ableism without grasping its interrelations with heteropatriarchy, white supremacy, colonialism and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of a subjugated 'other' from whom profits and status are extracted."[10] Such identities have been criminalized and contained through legislation, institutionalization, and sterilization.[11] Disability studies scholar Margaret Price describes this devaluation of and harm to disabled bodyminds, stating, "[w]e are placed in institutions, medicated, lobotomized, shocked or simply left to survive without homes,"[12] which produce(d) documentation around disability. And Allison C. Carey, Liat Ben-Moshe and Chris Chapman, in their book *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, speak about the intersections of race, class, disability, nationality and gender and incarceration:

> Sites of incarceration such as medical institutions, nursing homes, and prisons, emerge and take shape in interaction with each other as various populations are sorted, identified, and treated according to rationalities and practices which, while different in many ways,

[9] Mia Mingus, "Moving Toward the Ugly: A Politic Beyond Desirability," *Leaving Evidence* (blog), August 22, 2011, https://leavingevidence.wordpress.com/2011/08/22/moving-toward-the-ugly-a-politic-beyond-desirability/.

[10] Patty Berne, "Disability Justice – a Working Draft by Patty Berne | Sins Invalid," June 10, 2015, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne.

[11] Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010).

[12] Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (University of Michigan Press, 2011), 26.

all mark certain people as deviant and thus justifying controlling what they can and cannot do.[13]

These ways of surveilling, documenting, and controlling non-normative bodyminds, I argue, are intertwined with the power embedded in archival systems and processes of recording. Michelle Jarman, by integrating both race and disability critiques, traces the "long history of those benefiting by a power structure based upon white privilege using medical and psychiatric diagnoses to manufacture 'truths' of racial inferiorities."[14] Archives, although not explicitly named, serve as the material embodiment of psychiatric[15] and racial injustice in many of these examples, as they exhibit power and control over marginalized lives through documenting and categorizing stigmatized people that reinforce social stigmas.

Sara White, who began the conversation on how disability studies can influence archival theory, gestures at the power of archives and the history of oppression within different marginalized identities.[16] White's work incorporates disability studies' concept of embodiment and illustrates that how we understand disability heavily influences how we appraise, arrange,

[13] Liat Ben-Moshe, Chris Chapman, and Allison C. Carey, *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (Springer, 2014), x.

[14] Michelle Jarman, "Coming Up from Underground: Uneasy Dialogues at the. Intersections of Race, Mental Illness, and Disability Studies," in *Blackness and Disability: Critical Examinations and Cultural Interventions*, ed. Christopher M. Bell (East Lansing: Michigan State University Press, 2012), 9–29, 19.

[15] Katie Aubrecht, "Disability Studies and the Language of Mental Illness," *Review of Disability Studies: An International Journal* 8, no. 2 (October 15, 2014): 34–49; Noah Geraci, "Patient Experiences of Access to Mental Health Records" (Los Angeles, CA, University of California Los Angeles, 2016), eScholarship University of California, http://escholarship.org/uc/item/79x9w05q.

[16] Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," *The American Archivist* 75, no. 1 (2012): 109–24.

and describe fonds and collections.[17] Although focused around a method of "account[ing] for all disability experiences," she highlights the conflation of medicine and nationalism, citing the categorization of enslaved Black people, immigrants, and poor whites as "defective" and how archives served public anxieties of contagion.[18] Race and nationality, as well as sexuality, gender, and class have shared histories, both separate and interwoven, with disability, producing multiple systems that document, govern, and impact people's lives.

This framework is particularly valuable for archival studies because it provides a nuanced approach to marginality and intersectionality, interrogating how identities can be sites of privilege or oppression, and can function differently in different spaces,[19] including within archival spaces. Caswell cautions that archival pluralism should "avoid the pitfalls of claims of universality, inattention to power, silencing dissent, and collapsing of difference" that happens in religious pluralism.[20] To claim disability, Alison Kafer confers, is "to recognize the ethical, epistemic, and political responsibilities" of such a claim[21] and to draw *more attention to difference*, not less. An intersectional approach is crucial for understanding archival power as it highlights the differences in understandings of marginality as well as how, even if not recognized, disability has already been evident in critical approaches.

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[17] Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," *The American Archivist* 75, no. 1 (2012): 109–24.

[18] Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," *The American Archivist* 75, no. 1 (2012): 109–24.

[19] Kimberle Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6 (1991): 1241–99, https://doi.org/10.2307/1229039.

[20] Michelle Caswell, "On Archival Pluralism: What Religious Pluralism (and Its Critics) Can Teach Us about Archives," *Archival Science* 13, no. 4 (December 1, 2013): 273–92, https://doi.org/10.1007/s10502-012-9197-y, 288.

[21] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 13.

Most importantly, disability studies recognizes that many of the people affected by systems of ableism and the cultural oppression of bodies and minds may not identify as disabled. We can interrogate how people are affected by ableist ideals and cultural anxieties, and how those anxieties might intersect with other marginalized identities. "Anxiety about aging, for example, can be seen as a symptom of compulsory able-bodiedness/able-mindedness, as can attempts to 'treat' children who are slightly shorter than average with growth hormones; in neither case are the people involved necessarily disabled, but they are certainly affected by cultural ideals of normalcy and ideal form and function."[22] Although archival holdings may not contain records specifically on disabled subjects, I will demonstrate that records still can rely on descriptive practices of materiality that assume self-evident properties and thus risk universalizing experience. I will identify examples of disabled lives being affected by the power and authority ingrained in archives, and I will also apply this theory broadly to surface widespread forms of archival oppression that can be connected to disability. As Alison Kafer highlights, "rethinking our cultural assumptions about disability, imagining our disability futures differently, will benefit us all, regardless of our identities."[23]

Models of Disability: Medical, Social, Political/Relational

As discussed within Chapter One of this dissertation, disability studies scholarship has conceptualized models of disability in order to understand the ways in which disability is conceived, is constructed, and functions in society. I will briefly revisit three models of disability: the medical, the social, and the more recently developed political/relational to lay a

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[22] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 8.

[23] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 8.

foundation for this chapter. Through these models, disabled bodyminds and lives are understood differently and the way in which disability is understood can have drastic impacts on the way it's met by individuals, societies and cultures. I return to these models as a way to draw out the ways in which the medical model of disability places focus on disability as a 'self-evident' and stagnant characteristic of the bodymind, as well as how the political/relational model emerged through critical approaches to both the medical and social models of disability.

The medical model of disability places emphasis on the disabled individual—simultaneously individualizing and universalizing disability. Each disabled person is therefore expected to navigate inaccessible spaces, either by adjusting their expectations of accessibility or by finding their own solutions. For instance, sexologist and disability consultant Bethany Stevens writes about attending an inaccessible venue, whereby, after agreeing to enter through an alternate back-door entrance, "tucked away near the trash bins," that is supposedly wheelchair accessible, she is still confronted with a staircase. The inaccessibility of the building leaves her needing to make a decision either to be carried into the venue or not to attend the event.[24] Kafer notes that within the medical model, disability becomes "a personal problem afflicting individual people, a problem best solved through strength of character and resolve."[25] And the response to disability is to "'treat' the condition and the person with the condition rather than 'treating' the social processes and policies that constrict disabled people's lives."[26] Through the medical model, disability is distilled to a "knowable fact of the body" which "encompass[es] the whole of

[24] Bethany Stevens, "There Was No Access Into Her Vagina… Monologue," *Crip Confessions* (blog), March 4, 2015, http://cripconfessions.com/there-was-no-access-into-her-vagina-monologue/.

[25] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 4.

[26] Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: NYU Press, 1998),11.

one's identity"[27] instead of being a component of a complex existence, socially and culturally situated, where not all individuals have the same experience.

Developed as a response to the medical model, *the social model of disability* addresses the social constructs that inhibit disabled people from having equal access to opportunities and resources that would otherwise help them to "participate fully in society, to live independently, to undertake productive work and to have full control over their own lives."[28] Instead of lying within the disabled body or mind, "the problem of disability is located in inaccessible buildings, discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies."[29] Stairs, in Stevens experience, "create a functional 'impairment' for wheelchair users that ramps do not."[30]

Kafer's development of the political/relational model of disability builds off the social model by shifting away from understanding disability as a purely medical "problem" of the bodymind, understanding how social and architectural barriers can alienate non-normative bodies, and also incorporating queer and feminist critiques of identity.[31] Kafer's model, unlike

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[27] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 109.

[28] Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard Davis, 2 edition (New York: Routledge, 2006), 197–204, 200.

[29] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 6.

[30] Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, 1st edition (New York: Columbia University Press, 1996), 7.

[31] Kafer is one of a few disability studies scholars to use a relational model of disability. For example, Carol Thomas outlines "the social relational approach" to disability, exploring how disability is a site of oppression and is "a social relationship between people" (Thomas 1999). Tanya Titchkosky cites Judith Butler's exploration of "what it means to be a subject who is constituted in or as its relations" (Butler 2009, p. 49). Titchkosky states, "Whether or not disabled people will be told about the absence of essential services depends on many external factors and this is a way of constituting the subject of disability 'as its relation to the university'" (Titchkosky 2010). Allison C. Carey (Carey 2010a, 2010b) and Rosemarie Garland-Thomson have both written in detail about relational aspects of disability. Garland-Thomson states that "The relational reciprocity between body and world materializes both, demanding in the process an attentiveness to the distinctive, dynamic thing-ness of each as they come together in time and space" (Garland-Thomson 2011b, p. 595). Additionally, there is a "Nordic relational model" of disability that came out of Scandinavian scholars such as Simo Vehmas and Anders Gustavsson. I use Kafer's model since it is

the social model, does not differentiate between impairment and disability. Kafer's shift to a political/relational model frames disability as a pluralized political site that is ever-changing and always in relation to other people, environments, and attitudes, specifically by proposing disability as an *assemblage*. Originally developed by Deleuze and Guattari, an assemblage approach is an ontological shift in understanding the social complexity and fluidity of bodies, specifically with relation to exteriority.[32] They note that, "[t]he form of content is reducible not to a thing but to a complex state of things as a formation of power (architecture, regimentation, etc.)."[33] An assemblage, on one hand, is "machinic assemblage of bodies, of actions and passions, an intermingling of bodies reacting to one another; on the other hand it is a collective assemblage of enunciation, of acts and statements, of incorporeal transformations attributed to bodies."[34]

Working off of Jasbir Puar's use of assemblage theory, where categories such as race, gender, sexuality, and disability, "are considered as events, actions, and encounters between bodies, rather than as simply entities and attributes of subjects,"[35] Kafer highlights how an assemblage-like approach to disability links materials, processes, attitudes, and encounters across time. For example, Steven Kurzman traces the materials of his prosthetic leg to materials that are

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comprehensive, incorporates aspects of the aforementioned relational concepts, and, most importantly, utilizes Deleuze and Guattari's assemblage theory, which specifies the temporal, spatial, and material aspects of how disability is relational.

[32] Gilles Deleuze and Felix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi, 1St Edition edition (Minneapolis: University of Minnesota Press, 1987), 66-7.

[33] Gilles Deleuze and Felix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi, 1St Edition edition (Minneapolis: University of Minnesota Press, 1987).

[34] Gilles Deleuze and Felix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi, 1St Edition edition (Minneapolis: University of Minnesota Press, 1987), 88.

[35] Jasbir K. Puar, Ben Pitcher, and Henriette Gunkel, "Q&A with Jasbir Puar [Interview] | Darkmatter Journal," May 2, 2008, http://www.darkmatter101.org/site/2008/05/02/qa-with-jasbir-puar/.

based in military technology, have a history in post–Cold War production, and can only be accessed through a job which offers health insurance to reduce cost.[36] The materials in everyday life, including within archives and records, can be traced to systems of power and politics. Disability is therefore *political*, "as a set of practices and associations that can be critiqued, contested, and transformed;"[37] and *relational*, involving understandings, encounters, and interactions with individuals, built environments, and governing bodies. Under this model, the assemblage of disability becomes a multiplicity: it is a fluid identity that shifts over time and in different situations. A pluralized understanding of disability locates disability in bodyminds, cultural and social attitudes, architecture, and politics.

I situate this intellectual project within Kafer's political/relational model of disability because, as these examples demonstrate, disability is always already political. Through the social model we can see that certain constructs can be stigmatizing, but by using the political power of the formerly self-evident medicalized body and relational aspects of identity, we can open up archives and their processes as political as well as interconnected with other identities, systems, and societies that produced them. Just as societal norms become embodied within the standardized practices of an archives, so too does the definition and understanding of people produced by archives become ingrained in society. By not rejecting the medical model, but politicizing it alongside the social model, archives can be considered a political entity and that politicization can expose the oppressive political power that archives hold over marginalized people and the society that defines them. Understanding archives as assemblages—of people, places, policies, attitudes, environments, and materials across time—we can draw in the multiple

[36] Steven L. Kurzman, "Presence and Prosthesis: A Response to Nelson and Wright," *Cultural Anthropology* 16, no. 3 (2001): 374–87.

[37] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 9.

and expansive histories and entities that co-construct archival material and represent them within description.

A Political/Relational Model for Archival Description

Through the political/relational model of disability, the politicization of archival processes and systems can be revealed. Archival description, "the creation of an accurate representation of the archival material by the process of capturing, collating, analyzing, and organizing information that serves to identify archival material and to explain the context and records systems that produced it, as well as the results of these processes,"[38] is just one layer of how implicit and explicit bias is embedded in records and archives. When a record is first created, language and terms are used to title, describe, and categorize its contents, which are culturally and temporally situated. Once that record is accessioned into an archives, archivists inevitably must make decisions around further description, what language to use and how detailed to be, all of which stems from the archivist's positionality—their experiences, language, and knowledge of the subject, not to mention the positionality of the archives as reflected in its mission, anticipated audiences, and systems parameters. There are many other aspects that factor into how and if archival material is described, such as whether the processing of a fonds or collection is a priority, how the archive prioritizes processing material batches rather than individual items,[39] or if a donor has an interest in or litigation requires the processing of a particular collection.

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[38] The Society of American Archivists, "A Glossary of Archival and Records Terminology," accessed October 29, 2018, https://www2.archivists.org/glossary.

[39] Mark Greene and Dennis Meissner, "More Product, Less Process: Revamping Traditional Archival Processing," *The American Archivist* 68, no. 2 (Fall/Winter 2005): 208–63.

A political/relational approach to archival description is crucial to understanding the complexity of the process because the ways in which archival material is represented affects "the creation of access tools (guides, inventories, finding aids, bibliographic records) or systems (card catalogs, bibliographic databases, EAD databases)" designed for internal, public and/or scholarly use.[40] And this, in turn, affects everything that happens afterwards: how materials are found, understood, and subsequently used. I will show how, by linking archives to disability, the records description process, both at the time of creation as well as subsequent description by archivists, is always already politicized, and that an assemblage approach to records draws in the multiplicity of their subjects' experiences and the many co-creators of records. Additionally, by exploring description as not self-evident, the political/relational lens surfaces alternative contexts, histories, systems, and affect of archival material.

Many scholars have investigated the purpose descriptive language serves within an archives. Archival materials are often created and described by people in a position of relative power, in anticipation of the use to which those materials will be put. Ciaran Trace emphasizes how the creation of records and their description is not merely reactive, but also proactive; records can be created as byproducts of activity, but are more often created "in anticipation of the uses to which they may be put."[41] Trace gives examples of how law enforcement utilizes selective language in the production of arrest and interview records with a goal in mind around their future use. Records are described in order to seem authentic, "save time,… avoid unwanted

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[40] Elizabeth Yakel, "Archival Representation," *Archival Science* 3, no. 1 (2003): 1–25, https://doi.org/10.1007/BF02438926, 2.

[41] Ciaran B. Trace, "What Is Recorded Is Never Simply 'What Happened': Record Keeping in Modern Organizational Culture," *Archival Science* 2, no. 1–2 (March 1, 2002): 137–59, https://doi.org/10.1007/BF02435634, 144.

scrutiny,… [and] document cases that can be successfully resolved."[42] Similarly, not only can the words used about disability be harmful through the stigmatization of difference, but they have also historically been deployed, specifically within archives, as a means of enacting political authority.

A connection of archival description to feminist disability studies initiates a critical understanding of the political aspects of language. Disabled people have historically fought against oppressive language originating from non-disabled people: D/deaf people against "hearing impaired", wheelchair users against being "confined" to a wheelchair, people with chronic illnesses as "suffering" from illness, not to mention the infantilizing language that is often used to describe people with disabilities. Furthermore, language used to historically oppress disabled people is often deployed in day-to-day language to imply a negative connotation. Words such as "crippled, lame, dumb, idiot, moron"[43] and "crazy" have histories in the categorization of bodily and mental difference,[44] however, are used outside of that context to demean a person or object. Lydia X. Z. Brown articulates that

> Using the language of disability to denigrate or insult in our conversations and organizing presumes that a.) people who hold undesirable or harmful viewpoints must hold them because they are mentally ill/have psych disabilities/are mentally disabled/are disabled in some way, b.) having mental illness/psych disability/mental disability/any disability is actually so undesirable and horrible that you can insult someone that way (the same

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[42] Nancy Cochran, Andrew C. Gordon, and Merton S. Krause, "Proactive Records: Reflections on the Village Watchman," *Knowledge: Creation, Diffusion, Utilization* 2, no. 1 (September 1980): 5–18, 13.

[43] Rosemarie Garland-Thomson, "Integrating Disability Transforming Feminist Theory," in *Feminist Disability Studies*, ed. Kim Q. Hall (Bloomington: Indiana University Press, 2011), 13–47, 35.

[44] Katie Aubrecht, "Disability Studies and the Language of Mental Illness," Review of Disability Studies: An International Journal 8, no. 2 (October 15, 2014): 34–49.

underlying reason why socially embedded linguistic heterosexism lets people use "gay" as an insult), c.) it's acceptable to use ableism against one disability group while decrying ableism against another disability group (creating horizontal or intra-disability oppression) or another form of oppression against another marginalized group (creating horizontal oppression), and d.) and that no one who is disabled in any way might actually share your opinion or be on your side.[45]

The ways in which language about or around disability is used can affect people negatively—by perpetuating stereotypes and ableist assumptions, and by further stigmatizing difference—all point to the political aspects of language.

As Christopher Bell highlights, "disability shares much in common with other maligned identities insofar as departures from the norm are seen as threats to the mainstream body politic,"[46] and those anxieties became embodied within systems such as laws, regulations and archival processes through the criminalization and institutionalizations of disabled people. Nirmala Erevelles tell us that "Human variation (e.g. race) is deployed in the construction of disabled identities for purely oppressive purposes (e.g. slavery, colonialism, and immigration law)."[47] And Laura Briggs illustrates this by tracing how concepts of "hysteria" and nervousness were "located… in a scientific and popular discourse that defined cultural evolution as beginning

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[45] Lydia X. Z. Brown has also developed a glossary of such terms to encourage people to reflect on their own uses of ableist language (Brown 2012).

[46] Christopher M. Bell, ed., *Blackness and Disability: Critical Examinations and Cultural Interventions* (East Lansing: Michigan State University Press, 2012), 1.

[47] Nirmala Erevelles, "The Color of Violence: Reflecting on Gender, Race, and Disability in Wartime," in *Feminist Disability Studies*, ed. Kim Q. Hall (Bloomington: Indiana University Press, 2011), 117–35, 119.

with the 'savage,' culminating in the 'civilized.'"[48] Through a critical assessment of records that document how disability and illness were wielded to categorize white women as 'nervous' and women of color as 'savage,' Briggs highlights the example of Josephine Scott, "a free black woman living in Philadelphia in the 1870s and 1880s, an emigrant from the South and apparently a dwarf, whom her physicians accused of loose morals and who certainly was impoverished."[49] By addressing the language within records—such as nineteenth century issues of *American Journal of Obstetrics and Diseases of Women and Children* and *the American Obstetrical Society in Philadelphia*—Briggs demonstrates how multiple physicians justified medical experimentation on Scott through describing her "savage" qualities and thus her inability to feel pain. Description—within mainstream and scientific discourses and thus embodied within medical literature, records, and archival material—was wielded as a deliberate strategy to identify and justify discrimination against disabled people and people of color, which formed foundational theses in gynecological literature. The categorization of Scott's bodymind as 'savage' highlights, as Melissa Adler states, "the role that language and categories play in perpetuating and dispelling dominant myths and attitudes that sometimes do harm,"[50] and are constructed through cultural anxieties around difference. In Sarah White's identification of people classified as "deviant,"[51] Susan Schweik's tracing of people categorized as "unsightly,"[52]

[48] Laura Briggs, "The Race of Hysteria: 'Overcivilization' and the 'Savage' Woman in Late Nineteenth-Century Obstetrics and Gynecology," *American Quarterly* 52, no. 2 (2000): 246–73, 246.

[49] Laura Briggs, "The Race of Hysteria: 'Overcivilization' and the 'Savage' Woman in Late Nineteenth-Century Obstetrics and Gynecology," *American Quarterly* 52, no. 2 (2000): 246–73, 264.

[50] Melissa Adler, Jeffrey T. Huber, and A. Tyler Nix, "Stigmatizing Disability: Library Classifications and the Marking and Marginalization of Books about People with Disabilities," *The Library Quarterly* 87, no. 2 (March 16, 2017): 117–35, https://doi.org/10.1086/690734, 121.

[51] Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," The American Archivist 75, no. 1 (2012): 109–24.

[52] Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010).

Rosemarie Garland-Thomson's historical mapping of the word "monstrosity,"[53] and Briggs' focus on the "savage," description, representation, and categorization have worked as a means of power and control of not only disabled but also raced, classed, gendered, and sexualized bodyminds. The use of feminist disability studies for archival description facilitates an immediate connection to how "a record keeper's plans, goals, intentions and assumptions precede and therefore shape the record,"[54] by surfacing the scrutiny of language and the systems of historic violence disabled people have endured through archives.

Many scholars have highlighted, unpacked, and pushed back against the simplifying aspects of archival description that can be harmful to the records' subjects. Wendy M. Duff and Verne Harris point out that "[s]omething in the event being represented is always lost. There is always some distortion, even if only through incompleteness."[55] Contemporary work in archival studies has illuminated how a pluralist lens would liberate description from some of its oppressive power. Caswell has proposed a pluralist approach as "the acknowledgement of and engagement with, multiple coexisting archival realities—that is, fundamentally differing but equally valid ways of being and knowing—most commonly made manifest in the archival realm by (sometimes) irreconcilably divergent—but still credible—ways of defining, transmitting, and interpreting evidence and memory."[56] Similarly, Yakel has proposed that "[a]rchivists should

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[53] Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, 1st edition (New York: Columbia University Press, 1996).

[54] Nancy Cochran, Andrew C. Gordon, and Merton S. Krause, "Proactive Records: Reflections on the Village Watchman," *Knowledge: Creation, Diffusion, Utilization* 2, no. 1 (September 1980): 5–18, 16.

[55] Wendy M. Duff and Verne Harris, "Stories and Names: Archival Description as Narrating Records and Constructing Meanings," *Archival Science* 2, no. 3–4 (September 2002): 263–85, https://doi.org/10.1007/BF02435625, 275.

[56] Michelle Caswell, "On Archival Pluralism: What Religious Pluralism (and Its Critics) Can Teach Us about Archives," *Archival Science* 13, no. 4 (December 1, 2013): 273–92, https://doi.org/10.1007/s10502-012-9197-y, 277.

begin to think less in terms of a single, definitive, static arrangement and description process, but rather in terms of continuous, relative, fluid arrangements and descriptions as ongoing representational processes."[57] Incorporating queer theory into archival studies, Emily Drabinski points out the complexity inherent in description and that although librarians have worked hard to correct against incorrect classification, there is never a single stagnant answer to the question of how to describe archival material.[58]

Thinking alongside these scholars, I propose a political/relational archival approach to further a pluralized, relational understanding of records description, and more so, to expand upon the politicization of seemingly self-evident categories. A political/relational model, specifically around language, makes possible the surfacing of *archival assemblages*. An assemblage approach to archives not only draws in how language is wielded as a political tool, embedded in systems, as aspects of life are not always axiomatic, but also how description can include aspects such as people who may not be considered as either subject or creator of a record, a material's history and alternative uses, evolving social understandings of difference, and an archivist's positionality. Deleuze and Guattari caution against "considering tools in isolation: tools exist in relation to the interminglings they make possible or that make them possible,"[59] so situating records description among archival assemblages is crucial to illuminate how description is (and continues to be) a tool tied to cultural, temporal, and political conceptualizations.

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[57] Elizabeth Yakel, "Archival Representation," *Archival Science* 3, no. 1 (2003): 1–25, https://doi.org/10.1007/BF02438926, 4.

[58] Emily Drabinski, "Queering the Catalog: Queer Theory and the Politics of Correction," *The Library Quarterly: Information, Community, Policy* 83, no. 2 (2013): 94–111, https://doi.org/10.1086/669547.

[59] Gilles Deleuze and Felix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi, 1St Edition edition (Minneapolis: University of Minnesota Press, 1987), 90.

Using Deleuze and Guattari frameworks, Wendy M. Duff and Jessica Haskell argue that archives should adopt the concept of *the rhizome* in order to develop a less hierarchical approach to generating a multiplicity of descriptions and therefore user access.[60] A rhizome, which is the organizational structure of an assemblage, helps dismantle the authoritative voice of an archives by lacking traditional tree-like hierarchies. And, as Duff and Haskell demonstrate, this structure can be embodied in social media and web-based technologies to aggregate user-generated content. Just as the rhizome resists normative hierarchical structures, which is useful for organizing multiple perspectives, so too do assemblages, especially through a feminist disability studies lens, draw in the historical, social, and material aspects of descriptive processes. However, diverging from Duff and Haskell by focusing less on the *structure* of the rhizome and more on the *power* embedded in the layers of assemblages, this project takes a few steps back in order to instead center the layers of politics in which a record is situated.

Illuminating Archival Assemblages

It is to note that an assemblage approach towards archival description illuminates the complexity, power, and politicization of the mechanism of description, which functions not only in oppressive but also in liberatory ways within disabled peoples' lives. Medical records are prevalent and persisting examples of how disabled bodyminds are classified, controlled and regulated through description and classification systems. Medical records often describe people according to their difference from the (mythical) norm, as "ailments", and "abnormalities" are usually the predominant aspects documented. Although medical language is used to categorize people in medical records, the terminology permeates within archival descriptions. Language

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[60] Wendy M. Duff and Jessica Haskell, "New Uses for Old Records: A Rhizomatic Approach to Archival Access," The American Archivist 78, no. 1 (March 1, 2015): 38–58, https://doi.org/10.17723/0360-9081.78.1.38.

used within medical categorization and terminology is not isolated to the medical professional. As Kafer highlights, "what characterizes the medical model isn't the position of the person (or institution) using it, but the positioning of disability as an exclusively medical problem and, especially, the conceptualization of such positioning as both objective fact and common sense."[61] The simplification or complexity of disability represented within the language of description therefore has great impact on identity, understanding, and the relations of disabled people. Through diagnosis, medical providers can simplify the complex experience of disability, as well as control access to assistive devices and support systems. A politicized understanding of description surfaces the power of medical providers in potentially perpetuating limited understandings, rehabilitative approaches, and simplified systems to disability.

However, a diagnosis can also validate one's experience and provide language through which one can seek community. People with chronic illnesses, for example, can go their entire lives without having a diagnosis. Anna Hamilton writes about her ongoing experiences with getting a diagnosis when her symptoms were not "*consistent* with a textbook definition of *any* type of rheumatological issue."[62] Similarly, Rhonda Zwillinger highlights stories of the identification and diagnosis of Multiple Chemical Sensitivity that open up a world of community and resources for those who struggled to have their illness recognized.[63] Naming, therefore, can be understood as an oppressive and limiting force vis-à-vis the medical model, a way to gain access to medical systems and assistive devices, or a liberatory affirmation of experience and connection to new relations, people and resources.

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[61] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 5.

[62] Anna Hamilton, "Waiting," in *Criptiques*, ed. Caitlin Wood (May Day, 2014), 29–35, 33.

[63] Rhonda Zwillinger and Gunnar Heuser, *The Dispossessed: Living With Multiple Chemical Sensitivities* (Paulden, AZ: Dispossessed Project, 1998).

Building off of a complex notion of naming, archival assemblages challenge the self-evident-ness of the archival description. Sharon Barnartt highlights how the words used to describe disability "are categorical. They do not allow for a range. But impairments are not dichotomous conditions, in which one either has it or one does not."[64] Puar, working with assemblage theory, "argue[s] that the contradictions and discrepancies rife in this endeavor—creative mistakes, perhaps—are not to be reconciled or synthesized but held together in tension. They are less a sign of wavering intellectual commitments than symptoms of the political impossibility to *be on one side or the other*."[65] Just as the language we use is attached to history and politics, so too does the multiplicity of experiences in archival description have various connections, connotations, and histories. As Drabinski notes, "The entire project of library classification and cataloging is at odds with queer [and I would add crip] ideas about historicity, contingency, and the impossibility of a fixed system of linguistic signs that would contain identities that are always already relational and contingent."[66] Just as the ways in which disability functions among individuals, in different social contexts, and is constantly changing, so too do the words of description continually shift and hold contradictory perspectives.

The fluidity and situatedness of disability are useful mechanisms by which to critique any objects' description and to expose the assemblage of systems attached to a record. Like disability, records are culturally situated, multiply understood, and often contested between individuals. A political/relational approach to archival description expands upon scholarship that

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[64] Sharon Barnartt, "Disability As a Fluid State: Introduction," in *Disability As a Fluid State*, ed. Sharon Barnartt, vol. Volume 5, Research in Social Science and Disability (Bingley: Emerald Group Publishing, 2010), 2.

[65] Jasbir Puar, *Terrorist Assemblages: Homonationalism in Queer Times* (Durham: Duke University Press Books, 2007), 209.

[66] Emily Drabinski, "Queering the Catalog: Queer Theory and the Politics of Correction," *The Library Quarterly: Information, Community, Policy* 83, no. 2 (2013): 94–111, https://doi.org/10.1086/669547, 101.

has identified some of the ways in which archival processes ingrain and inscribe biases, and surfaces assemblages by challenging the self-evident-ness—what is thought of as objective and inherent to an object—and focusing on the semantic, epistemic and ontological changes in language. In the following examples, I will show how description's reliance on the self-evident-ness of archival material misses the complex, competing, and contradictory aspects of archival material. The fundamental contestation of description initiates the archival assemblage by drawing attention not only to how archives are, quite literally, assembled collections of material, but also how they are temporally, spatially, and materially contingent. A political/relational approach is first about moving away from the replication and reliance on self-evident properties of a record and second about addressing, not redressing, contestable terms, both of which illuminate the archival assemblages which produced it.

Through this lens, the language used not only in the World's Congress Auxiliary circular but also replicated and simplified in the Chicago Public Library online finding aid emphasizes multiple histories and systems of power. Created by The International Congress of Charities, Correction and Philanthropy, this record prioritizes the perspectives of the people in power who were invested in and determined who was in need of "moral and social reform." Simply represented as "Department of Moral and Social Reform, The International Congress of Charities, Correction and Philanthropy" within the online finding aid, an awareness of how rhetorics such as charity, corrections, and moral and social reform are connected to a body politic of disability helped me locate this record in the first place. These intertwined systems of reform, charity, and institutionalization are exemplified and embodied in many records around disability, like those created because of the ugly laws. Records such as arrest records, asylum documentation, and evolving legislation give a clear example of the political/relational

assemblage attached to this record. The ugly laws produced and were produced by city and state ordinances, public service surveys, and newspaper articles all of which create and influence stigma. And such records often describe marginalized people from a place of power. Likewise the contents of the circular, describing the events, presentation, and subjects to be addressed throughout "June 12-18, 1893," demonstrate intertwined hierarchies: general sessions such as "The Prevention and Repression of Crime and the Punishment and Reformation of Criminals," "The Custodial Care and the Training and Development of the Feeble-minded," and "Manual Training in its Effects on Character and the Reduction of Pauperism," as well as a "Visit to the Eastern Hospital for the Insane in Kankakee, IL., by special train. Luncheon will be served on the train,"[67] show how hierarchies of disability, class, and morality become enmeshed in rhetorics of reform.

Yet this record's description in the online finding aid omits many of these details. Kim Anderson notes that "many social transactions are not physically captured, and thus the records retained in the archive will tend to emphasize institutions or communities that communicate or conduct interactions in ways that can be captured."[68] The International Congress of Charities, Correction and Philanthropy record demonstrates just this as it is described within the "World's Congress Auxiliary Pre-Publications, Programs and Circulars Collection" within the "Department of Moral and Social Reform" section, as simply "The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892)." Accompanying these

[67] "The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892)," World's Congress Auxiliary Pre-Publications, Programs and Circulars Collection (Department of Moral and Social Reform, 1893 1889), Box 3 Folder 58, Chicago Public Library, https://www.chipublib.org/fa-worlds-congress-auxiliary-pre-publications-programs-and-circulars-collection/.

[68] Kimberly Anderson, "The Footprint and the Stepping Foot: Archival Records, Evidence, and Time," *Archival Science* 13, no. 4 (December 1, 2013): 349–71, https://doi.org/10.1007/s10502-012-9193-2, 357.

data are its location within the collection, "Box 3, Folder 58," the collection's physical properties, "2.5 linear feet," as well as the processing archivist.[69] Missing are the voices of those whose lives were affected by these categories, national and international initiatives, as well as the institutions, legislation, enforcements, and systems that produced and were produced by it.

Understanding this record through a political/relational lens links it not only to its creators and subjects but also to the many other types of records. This lens facilitates framing this record within a body of documents produced for hegemonic oppression, across city, state, and national borders through local, national, and global political climates operating throughout its life. Thinking through this record as an assemblage extends *broadly*, to the systemic and dominant discriminatory attitudes across time that formed and perpetuated systems of criminalization and institutionalization under the guise of 'charity', 'correction', 'reform' or 'rehabilitation'. And it also hones in *specifically*, to "each specific moment of… enforcement—each encounter between policeman, judge, friendly visitor, or sympathetic rabble-rouser and a particular person being found unsightly [or immoral]—and the broader social order that framed, ignored, fought over, and accepted" such rhetorics.[70] The current description of "self-evident" properties of the circular, such as date range of meetings and the department within the World's Congress Auxiliary, lacks the acknowledgement of how records are created in relation *to each other* (e.g. how the sessions exemplified existing practices that generated hundreds of arrest records, newspaper articles, and additional legislation around the documentation of disabled, racial or ethnic minorities, and those perceived as criminals), *to other people* (e.g. the many

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[69] "The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892)," World's Congress Auxiliary Pre-Publications, Programs and Circulars Collection (Department of Moral and Social Reform, 1893 1889), Box 3 Folder 58, Chicago Public Library, https://www.chipublib.org/fa-worlds-congress-auxiliary-pre-publications-programs-and-circulars-collection/.

[70] Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010), 141.

attendees being educated on methods of 'reform', those who enforced, made public outcries around "safety", and those who were criminalized and institutionalized, such as those on display at "Visit to the Eastern Hospital for the Insane"), *to societal systems* (e.g., the ways in which this records is situated among evolving bodies of legislation and in complex histories in relation to societal norms and was part of an international World's Fair that centered around Western ideals and white supremacy), and *to archives* (e.g., the influence archivists have over the creation, selection, and contextualizing of records). This all points to how the creation of records is designed to produce an effect,[71] whether that be for the oppression of particular communities or for the efficiency of the record keeper's job, that archival description can risk perpetuating or erasing.

A political/relational archival approach can also be applied broadly, beyond records that explicitly contain disabled people and to many types of collections. A disability-informed critique, as I will show, destabilizes what is thought of to be self-evident in description while also allowing broad ties to disability. Museum objects, for example, can also be records, as they provide evidence of an activity that persists throughout time[72] and also use descriptive practices to represent material. Cara Krmpotich and Alexander Somerville describe the evolution of a museum artifact known as the "S BLACK" bag.[73] And Laura Peers traces its multiple catalog descriptions, stating that "Since its arrival at the [Pitt Rivers Museum at the University of Oxford

[71] Ciaran B. Trace, "What Is Recorded Is Never Simply 'What Happened': Record Keeping in Modern Organizational Culture," *Archival Science* 2, no. 1–2 (March 1, 2002): 137–59, https://doi.org/10.1007/BF02435634, 155.

[72] Geoffrey Yeo, "Concepts of Record (1): Evidence, Information, and Persistent Representations," *The American Archivist* 70, no. 2 (2007): 315–43.

[73] Cara Krmpotich and Alexander Somerville, "Affective Presence: The Metonymical Catalogue," *Museum Anthropology* 39, no. 2 (September 1, 2016): 178–91, https://doi.org/10.1111/muan.12123.

(PRM)] it has been identified as '1893.67.183', and first as 'Embroidered bag with bead ornament' and later as 'Black cloth "octopus" bag, bead-edged, with floral and double-curve motifs and the name "S BLACK" embroidered in coloured thread, and beaded wool tassels'."[74] Through its sparse and decontextualized description in the PRM catalog, the bag's history, specificities and cultural affect have been erased.[75]

Native communities have long worked to decolonize multiple facets of museum material and descriptions as well as problematize settler colonial language used to describe cultures.[76] An assemblage intervention in no way intends to erase the vast and effective work being done by Indigenous peoples. Utilizing a feminist disability studies approach alongside these works thinks through how anti-oppression projects can work in tandem to provide multiple avenues for

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[74] Laura Peers, "'Many Tender Ties': The Shifting Contexts and Meanings of the S BLACK Bag," *World Archaeology* 31, no. 2 (October 1, 1999): 288–302, https://doi.org/10.1080/00438243.1999.9980447.

[75] Cara Krmpotich and Alexander Somerville, "Affective Presence: The Metonymical Catalogue," *Museum Anthropology* 39, no. 2 (September 1, 2016): 178–91, https://doi.org/10.1111/muan.12123.

[76] Ellen Hoobler, "'To Take Their Heritage in Their Hands': Indigenous Self-Representation and Decolonization in the Community Museums of Oaxaca, Mexico," *The American Indian Quarterly* 30, no. 3 (September 6, 2006): 441–60, https://doi.org/10.1353/aiq.2006.0024; Norman K. Denzin and Yvonna S. Lincoln, "Introduction: Critical Methodologies and Indigenous Inquiry," in *Handbook of Critical and Indigenous Methodologies*, ed. Norman K. Denzin, Yvonna S. Lincoln, and Linda Tuhiwai Smith, 1 edition (Los Angeles London New Delhi Singapore: SAGE Publications, Inc, 2008), 1–20; Shannon Faulkhead, "Connecting through Records: Narratives of Koorie Victoria," *Archives and Manuscripts* 37, no. 2 (November 2009): 60; Sue McKemmish, Shannon Faulkhead, and Lynette Russell, "Distrust in the Archive: Reconciling Records," *Archival Science* 11, no. 3 (November 1, 2011): 211–39, https://doi.org/10.1007/s10502-011-9153-2; Amy Lonetree, *Decolonizing Museums: Representing Native America in National and Tribal Museums* (Univ of North Carolina Press, 2012); Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples*, 2 edition (London: Zed Books, 2012); Marisa Elena Duarte and Miranda Belarde-Lewis, "Imagining: Creating Spaces for Indigenous Ontologies," *Cataloging & Classification Quarterly* 53, no. 5–6 (July 4, 2015): 677–702, https://doi.org/10.1080/01639374.2015.1018396; Sandra Littletree and Cheryl A. Metoyer, "Knowledge Organization from an Indigenous Perspective: The Mashantucket Pequot Thesaurus of American Indian Terminology Project," *Cataloging & Classification Quarterly* 53, no. 5–6 (July 4, 2015): 640–57, https://doi.org/10.1080/01639374.2015.1010113; Bryony Onciul, *Museums, Heritage and Indigenous Voice: Decolonizing Engagement* (Routledge, 2015); Hannah Turner, "Decolonizing Ethnographic Documentation: A Critical History of the Early Museum Catalogs at the Smithsonian's National Museum of Natural History," *Cataloging & Classification Quarterly* 53, no. 5–6 (July 4, 2015): 658–76, https://doi.org/10.1080/01639374.2015.1010112; Jane Anderson and María Montenegro, "Collaborative Encounters in DigitalCultural Property," in *The Routledge Companion to Cultural Property*, ed. Jane Anderson and Haidy Geismar, 1 edition (London ; New York: Routledge, 2017), 431–51; María Montenegro, "Subverting the Universality of Metadata Standards," *Journal of Documentation*, July 8, 2019, https://doi.org/10.1108/JD-08-2018-0124.

archivists to critically reflect on power structures and reach beyond simplified descriptive practices in intersectional ways.

Similar to the medical model of disability, description can be problematic because it oversimplifies the experience of one's existence, either because it is assumed to be self-evident or because their experience is not known. As Krmpotich, Somerville and Peers point out, the descriptions in the PRM catalog rely on the axiomatic materiality of the bag. Through their analyses as well as through a critical assessment of the medical model of disability, we can begin to appreciate "the limitations of existing controlled vocabularies" as well as "the language and the scripts in which description is rendered"[77] as limited to western understandings of Native peoples' realities and the complexity of their material culture, not to mention the "lost and acquired meanings when it began this part of its life as a museum artefact."[78] The description, "Black cloth 'octopus' bag, bead-edged, with floral and double-curve motifs and the name 'S BLACK' embroidered in coloured thread, and beaded wool tassels," reduces this object to only its materiality, as if self-evident. Without acknowledgement of the bag's political and relational properties, as within the medical model, archival description documents material according to its material difference, assumes self-evident properties, and thus risks universalizing the experiences of those who made or use(d) this type of bag.

Through a political/relational archival approach to description, the S BLACK bag's complex histories can resurface. An assemblage perspective multiplies understandings of the material and situates it as defined by western societal and cultural norms. Politicizing the bag's

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[77] Stacy Wood et al., "Mobilizing Records: Re-Framing Archival Description to Support Human Rights," *Archival Science* 14, no. 3–4 (October 1, 2014): 397–419, https://doi.org/10.1007/s10502-014-9233-1, 408.

[78] Laura Peers, "'Many Tender Ties': The Shifting Contexts and Meanings of the S BLACK Bag," *World Archaeology* 31, no. 2 (October 1, 1999): 288–302, https://doi.org/10.1080/00438243.1999.9980447, 297.

representation illuminates the colonialist imperatives of the fur trade that displaced the bag and the multiple changes of hands that took place for it to finally make it to the PRM. Understanding this object as relational means noticing the specific materials, processes, and relations that went into the making of the bag as well as drawing in those who co-constructed its meaning. This style of bag, Peers notes, was usually an intimate gift and a symbol of kinship and care. Through a relational approach, the bag's affective history and familial and communal ties are located by situating it with who made it and for what reasons.[79] If archival description is considered a politicized effort, then the reduction of its complex histories to its materiality are a political move, made by someone with a specific positionality. Politicizing this description can reintroduce these complex histories and produce a contestation of the language and methods used to describe material as well as the authoritative voice from which it came.

Furthermore, the attention drawn to the multiple histories of the bag, like many of the examples in this chapter, temporally ties the current description to its colonial history, which highlights both the interconnected oppression between Indigenous peoples and disabled people as well as the ongoing processes that *maintain power* in an archives. A feminist disability studies lens draws in the ways in which "colonists tied ablebodiedness to compulsory productivity and racialized heteronormativity,"[80] how projects of civilization and normalization are historically linked through endeavors such as colonization, eugenics, and institutionalization.[81] For example,

[79] Ellen Pearlstein, "Conserving Ourselves: Embedding Significance into Conservation Decision-Making in Graduate Education," *Studies in Conservation* 62, no. 8 (November 17, 2017): 435–44, https://doi.org/10.1080/00393630.2016.1210843.

[80] Adria L. Imada, "A Decolonial Disability Studies?," *Disability Studies Quarterly* 37, no. 3 (August 31, 2017), http://dsq-sds.org/article/view/5984.

[81] Penelope Kelsey, "Disability and Native North American Boarding School Narratives: Madonna Swan and Sioux Sanitorium," *Journal of Literary & Cultural Disability Studies* 7, no. 2 (August 22, 2013): 195–211; Siobhan Senier and Clare Barker, "Introduction to Special Issue: Disability and Indigeneity," *Journal of Literary & Cultural Disability Studies*, Special Issue: Disability and Indigeneity, 7, no. 2 (August 22, 2013): 123–40; Robert Warrior,

Siobhan Senier and Clare Barker illustrate the many connections of disability within colonial power: not only did European settlers bring smallpox and other diseases that Indigenous peoples weren't immune to, but also how Indigenous people are framed as genetically inferior, "predisposed to alcoholism, diabetes, or other conditions," which is used to justify the violence of boarding schools, TB wards, prisons, and other institutionalization aimed at the 'rehabilitation' of Native people. They state, "Narratives of indigenous pathology are anything but subtle when it comes to underwriting colonialism."[82] Adria Imada illustrates how those who were colonized are always already figured as disabled:

> Colonial projects imposed impossible regimes and expectations of self-regulation its subjects would not be able to perform. Thus, the colonized were always already figured and constituted as disabled, whether because of their perceived unproductivity as laborers; embodied racial-sexual differences; 'unchaste' proclivities of their women; susceptibility to moral contagion and infectious diseases; or inability to learn.[83]

Senier and Barker poignantly propose:

> we might say that while settler colonialism has constructed indigenous people as ill or disabled discursively, it has also produced indigenous illness and disability materially. In this way, settler colonial ideologies of assimilation closely resemble the ideologies of

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The World of Indigenous North America (Routledge, 2014); Laura Jordan Jaffee, "Disrupting Global Disability Frameworks: Settler-Colonialism and the Geopolitics of Disability in Palestine/Israel," *Disability & Society* 31, no. 1 (January 2, 2016): 116–30, https://doi.org/10.1080/09687599.2015.1119038; Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham London: Duke University Press Books, 2017).

[82] Siobhan Senier and Clare Barker, "Introduction to Special Issue: Disability and Indigeneity," *Journal of Literary & Cultural Disability Studies*, Special Issue: Disability and Indigeneity, 7, no. 2 (August 22, 2013): 127.

[83] Adria L. Imada, "A Decolonial Disability Studies?," *Disability Studies Quarterly* 37, no. 3 (August 31, 2017), http://dsq-sds.org/article/view/5984.

normalization described by Lennard Davis and others, operating both to produce identity (as indigenous and/or disabled) and to mask it.[84]

Meeskoka and Shuttleworth highlight that "Disabled people in the majority world have been marginalised often as a result of colonisation, colonial rule and post-colonialism; these cases constitute 80 per cent of the 650 million disabled people in the world."[85] In other words, as these works show, a medicalized disability, intertwined with ontologies of knowing, methods of 'fixing', and histories of oppression, works in service of a settler colonial project. Disability is part of colonial history through the ways in which interlocking systems operate, how disability and illness are caused through colonial endeavors, and how ableism functions to frame certain cultures and people as inferior in service of colonial agendas.

Through an attention to these interconnected histories, contemporary archival interventions that simply replicate past descriptions (or versions thereof) risk a temporal separation from oppression, threatening both an object's dynamism and contingencies to time and place as well as how the violence of the past can be understood as an ongoing settler colonial project[86] that is sustained through archival description. Understanding this bag as an assemblage of people, systems, and languages allows for a connection of the S BLACK bag's history to parallel and intertwined settler colonial projects of eugenics and ableism. Therefore, with a critical lens trained on the axiomatic description(s) of the bag, one can also consider the systems

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[84] Siobhan Senier and Clare Barker, "Introduction to Special Issue: Disability and Indigeneity," *Journal of Literary & Cultural Disability Studies*, Special Issue: Disability and Indigeneity, 7, no. 2 (August 22, 2013): 123–40, 129.

[85] Helen Meekosha and Russell Shuttleworth, "What's so 'Critical' about Critical Disability Studies?," *Australian Journal of Human Rights* 15, no. 1 (November 1, 2009): 47–75, https://doi.org/10.1080/1323238X.2009.11910861, 64

[86] Mark Rifkin, *Settler Common Sense: Queerness and Everyday Colonialism in the American Renaissance*, 1 edition (Minneapolis ; London: Univ Of Minnesota Press, 2014).

through which Indigenous people were (and are) both harmed or debilitated through the fur trade—the violence of colonialism as well as the introduction of disease—as well as possibly devalued or figured as already disabled through colonial lenses that could have justified the bag in the first place. Furthermore this makes space for the opening up of questions around how the colonial devaluation of Indigenous perspectives might allow for the continued use of "self-evident" description and not an expansive depiction of its historical and contemporary connections. Through a disability-informed and political/relational lens, we can understand the relational elements of the bag itself as well as how the histories in which it is embedded are also connected to disability and ableism.

Not only through this lens would an archivist be more likely to reflect on their own positionality and the assemblage of people, interactions, and decisions that went into making the object itself, but also archivists and archival users alike would consider all of the people, systems, governing bodies, interactions, attitudes, and decision-making processes that produced the object within an archives and could contend with it in the present. This framework can facilitate archivists in further understanding how language used within archival description erases Indigenous knowledges around affect and relationality. Moreover, it can illuminate the parallel and intertwined oppressions of settler colonial projects, eugenics, and ableism—the ways in which settler colonialism obscures certain knowledges, erases certain histories, and flattens or essentializes material—building archival solidarity between anti-ableist and anti- or de-colonial archival approaches. This approach can therefore serve to identify histories of disability and ableism even when they may not be readily apparent in records.

So, what can we as archivists do? The power of description, when viewed as an assemblage, highlights old and creates new relations in different contexts. "In describing records,

archivists are working with context, continually locating it, constructing it, figuring and refiguring it."[87] Contextualizing archives as assemblages makes space for the inclusion and recognition of counter narratives and also recognizes and makes apparent other influences, such as budgetary limits and archival traditions, on how descriptions are produced. Retroactively exposing the complexity and multiplicity of the creation of some records may be almost impossible for archivists; however, it is possible to research subjects, creators, institutions, and political climates around the creation of a record and reflecting that complexity within an archives. This paper, alongside Native communities that have long advocated for the decolonization of museum and archival material, advocates for community leadership in complicating, renaming, and redescribing records. This article encourages archivists to seek out expansive counternarratives that connect related records, expose the politics of the archive's intervention(s), challenge seemingly self-evident categories, and expose new histories of disability that may not be obvious.

What might this look like? By utilizing feminist disability studies, this chapter—instead of identifying solely functional problems and thus providing concrete solutions—aims to offer a theoretical starting point to encourage archivists to seek creative solutions to how the multimodal inclusion of multiple perspectives, material histories, and assemblages of disparate connections might be implemented. Duff and Haskell, through digital technologies, emphasize, "develop[ing] collaborative frames supported by nonhierarchical, acentric systems that foster open, dynamic, radical, political, and subjective access,"[88] which is a valuable start to thinking through systems

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[87] Wendy M. Duff and Verne Harris, "Stories and Names: Archival Description as Narrating Records and Constructing Meanings," *Archival Science* 2, no. 3–4 (September 2002): 263–85, https://doi.org/10.1007/BF02435625, 276

[88] Wendy M. Duff and Jessica Haskell, "New Uses for Old Records: A Rhizomatic Approach to Archival Access," *The American Archivist* 78, no. 1 (March 1, 2015): 38–58, https://doi.org/10.17723/0360-9081.78.1.38, 42.

design.[89] However, focusing only on the democratizing aspects of the rhizomatic structure of archival material, while elevating voices who may have been previously devalued,[90] risks erasing the history of the power embedded in archival material. Equalizing all contributions to a record's description to the same level gestures at "correcting" previous power structures, whereas an assemblage approach highlights how power is always already (and continually) involved in description.

Evoking Drabinski once again, who advocates against to go beyond the "fixing" of problematic or outdated descriptive terms, this project does not promote the preservation of the power relationships, but does not advocate for the erasure of them either. Angela DiVeglia notes, "[b]ringing a painful past to light can be legitimizing in that it allows community members to recognize and mourn for ways in which their predecessors have been harmed, while producing accountability for governments and social forces that have persecuted LGBT [and other marginalized people] people throughout history."[91] Highlighting the power relationships in archival description keeps these histories at the forefront and places the responsibility on the archivists to continually address them. An assemblage approach, therefore, instead of flattening all perspectives to the same level, asks how the history of power can be represented. This is a call to create more complex archival systems to represent all of these relationships. Should we create separate sections in databases for an archivist to list their positionality? Should there be

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[89] Haidy Geismar and William Mohns, "Social Relationships and Digital Relationships: Rethinking the Database at the Vanuatu Cultural Centre," *Journal of the Royal Anthropological Institute* 17 (May 1, 2011): S133–55, https://doi.org/10.1111/j.1467-9655.2011.01693.x.

[90] Wendy M. Duff and Jessica Haskell, "New Uses for Old Records: A Rhizomatic Approach to Archival Access," *The American Archivist* 78, no. 1 (March 1, 2015): 38–58, https://doi.org/10.17723/0360-9081.78.1.38.

[91] Angela DiVeglia, "Accessibility, Accountability, and Activism: Models for LGBT Archives," in *Make Your Own History: Documenting Feminist and Queer Activism in the 21st Century*, ed. Kelly Wooten and Lyz Bly (Los Angeles, CA: Litwin Books, LLC, 2012), 69–104, 75.

guidelines for what to include within a record's assemblage and how far outward to expand? How might we create links to other records that may seem unrelated and what are the implications of connecting them? And how might these new connections create new questions around privacy and identity?

With the current ubiquity of digital technologies in archives (for both internally used digital databases and catalogs, as well as public facing digital archives), a political/relational archival assemblage is a jumping off point to consider how we can incorporate as much of the assemblage as possible. It is an epistemological shift in what archivists consider when describing material and who they seek out to assist them. By thinking through the multiple models of disability, feminist disability studies shifts the responsibility away from the individual, who is relied upon to navigate relations to power (by having materials, experiences, and subjects listed as self-evident)—as is the case with the medical model—towards the collective responsibilization of access and attitudes (to actively engage with communities to participate in describing material)—as through the social model—and furthermore, addresses the modes of power that operate that produce dynamics (by asking how we can represent the complex histories and expansive connections of a record)—as with the political/relational model.

Conclusion

There is inherent power in the creation of records, the formation of archives, and the ways in which archival material is described and processed. Feminist disability studies opens up archival processes as sites for contestation and exposes the layers of power within an archives. A connection to disability, through a political/relational archival approach, first provides an immediate politicization of archival systems by surfacing the power of language as well as how archives have been historically used against disabled people. This connection also challenges

archival description as fixed and self-evident. As description happens multiple times such as when a record is created and when it enters an archives, this framework is a starting point for critiquing the reliance on self-evident qualities and thus the potential to further replicate historic power structures. Most importantly, the framework expands and connects the assemblage of people, places, politics, systems, attitudes, and histories that may or may not be obvious and that have influenced and continue to influence archives, archival processes, archivists, and different users. It resists simply correcting outdated terms and instead turns towards the inclusion of multiple complex and possibly contested perspectives. As the process of describing materials is linked heavily to the development of catalogs and finding aids, an epistemological shift through a political/relational approach to archives helps draw in the assemblages to which a record is connected. As a practical framework, it is a starting point for a criticality of language used in description and an expansive representation within a record as well as another avenue for archivists to think through intersectional anti-oppression projects. However, this is not a singular solution but rather a call for archivists to think creatively about how digital tools can represent dynamic relations and politics of archival material, which could include the acknowledgement of multiple authors in different aspects of the description, the tracing of a particular material's history to its alternate uses, or links to other records that were created through the same power structures.

I cannot ignore the power of naming in this archival assemblage of the "The International Congress of Charities, Correction and Philanthropy. Circular #2 (December 1, 1892)." Duff and Harris articulate that "[w]hat we name we declare knowable and controllable."[92] Those labeled

[92] Wendy M. Duff and Verne Harris, "Stories and Names: Archival Description as Narrating Records and Constructing Meanings," *Archival Science* 2, no. 3–4 (September 2002): 263–85, https://doi.org/10.1007/BF02435625, 281.

as "feeble-minded," "delinquent," and "insane" were stigmatized through the use of these words within the record and most likely had the rest of their lives dictated by this categorization. Simi Linton says that "[i]t has been particularly important to bring to light language that reinforces the dominant culture's view of disability."[93] A person documented as "feeble-minded" not only becomes permanently labeled as such, but also, the use of these words in records creates a public standard of acceptance of the categorization and fear of particular people. The representation of these classification systems, represented in the Chicago Public Library's finding aid only as "The International Congress of Charities, Correction and Philanthropy" within the "Department of Moral and Social Reform," without context or connection to their political assemblages, reinforces the how the medical model manifests and has the potential to further stigmatize people with disabilities. Archival description is an opportunity to offer more. Through this close look at this record, we can understand how records creation and description defines and "(re)enforce[s] racial [and other] bias and the interests of dominant power structures."[94] Archival processes are not only influenced by cultural systems, attitudes, biases and norms, but they also create them.

In some ways, I am grateful for the aches I feel when reading the harmful language used in the circular. To feel so deeply the pain of language used against people, that affects so many lives, feels like an appropriate affective response to systemic violence. To acknowledge the use of harmful language within records and illustrate the history of oppression instead of ignoring it or correcting it becomes a valuable task for archivists to involve those affected by that language. Like the term "queer", "crip" (as in crippled) has been reclaimed as a political identity by many

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[93] Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: NYU Press, 1998), 9.

[94] Anthony W. Dunbar, "Introducing Critical Race Theory to Archival Discourse: Getting the Conversation Started," *Archival Science* 6, no. 1 (March 1, 2006): 109–29, https://doi.org/10.1007/s10502-006-9022-6, 116.

disabled people. Nancy Mairs saliently states, "People—crippled or not—wince at the word 'crippled' as they do not at 'handicapped' or 'disabled.' Perhaps I want them to wince."[95] This project, like the projects of Puar and Drabinski, promotes acknowledging the prevalence of discrimination against certain identities instead of erasing or obscuring it.

A political/relational archival approach helps me recognize that the lives represented in each session of the circular are connected to each other, as a body of evidence of the violence endured by those incarcerated, and to a larger cultural climate that encouraged the incarceration and labeling of disabled people. This lens allows me to keep in mind the history of ableist oppression while simultaneously realizing that the experiences of the record's subjects, as well as of each World's Congress Auxiliary member, WCE visitor, doctor, orderly, archivist, or witness, are differing and diverse. The history, context and diversity of experiences are absent from this record's description, and I know that providing the context and complexity of a record within its description isn't an easy feat. However, by prioritizing this lens, archivists would be more likely to educate themselves, link to outside sources, and invite the participation of disabled people and marginalized communities in the description and representation of records about them or their community[96]—all of which would provide users with a broader and more diverse experience while resisting the erasure of past harms.

An assemblage approach draws attention to positionality and leaves room for archivists to invite subjects and those affected to co-create and reclaim their narratives. Corbett O'Toole points out how some disability studies scholars have decreased their involvement with disabled

[95] Nancy Mairs, *Plaintext: Essays*, Reprint edition (Tucson: University of Arizona Press, 1992), 9.

[96] Katie Shilton and Ramesh Srinivasan, "Participatory Appraisal and Arrangement for Multicultural Archival Collections," *Archivaria* 63, no. 0 (2007): 87–101; Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," *The American Archivist* 75, no. 1 (2012): 109–24; Stacy Wood et al., "Mobilizing Records: Re-Framing Archival Description to Support Human Rights," *Archival Science* 14, no. 3–4 (October 1, 2014): 397–419, https://doi.org/10.1007/s10502-014-9233-1.

community members, those who "are in dire need of useful scholarship that can help us articulate critical issues, develop new ideas, and quantify community experiences in order to drive both conversations and policies."[97] Her words resonate for archival practitioners as well. The well-known phrase from the disability community, "nothing about us without us," calls to action the involvement and agency of disabled voices in material about their communities. A diverse array of disabled people, from both inside and outside of academia, should be involved in (and compensated for) describing archival material around disability, not only to produce an expansive assemblage around archival material, but also to address, as O'Toole highlights, "The ongoing and entrenched barriers facing community scholars within disability studies [that] include: economic barriers to participation, structures that prioritize nondisabled people or people with the least impairing disabilities, an embedded and unacknowledged focus on white people, and a refusal to provide economic compensation for the contributions of community scholars."[98] To conceptualize an archival assemblage is to consider one's participation and positionality in it, thus encouraging archivists to involve subjects in describing material that represents their communities.

Existing at the intersection of disability studies, feminist discourse, and archival studies, this chapter builds theory around archival description and shows how a crip provenance can not only highlight the *systems* that produced a single record or fonds, but also all of the interlocking systems that created and influenced the creation of other records, entangled with legislation, archival processes, attitudes, language, and records across time. Like societal provenance, this

[97] Corbett Joan O'Toole, "On the Importance of Community Scholars in DS," *Disability Studies Quarterly* 37, no. 3 (August 31, 2017), http://dsq-sds.org/article/view/5896.

[98] Corbett Joan O'Toole, "On the Importance of Community Scholars in DS," *Disability Studies Quarterly* 37, no. 3 (August 31, 2017), http://dsq-sds.org/article/view/5896.

chapter has looked to the systems that produce records as a way to add context to records and consider all of those involved in the ways records are represented within archives. However, by not solely orienting backwards nor aiming to reconstruct a ‘complete’ provenance, this lens facilitates destabilizing self-evident categories and connecting seemingly disparate sources as a part of an assemblage to expand archival description. This chapter has argued that an archival assemblages approach not only facilitates complicating how disability is represented in records but also shows that a disability-centered critique of language can open up contestation of the process of categorization and include such contestation in archival description. Central to a crip provenance, as this chapter has shown, is considering the systems that give context to records; through the ways in which records or objects are created, appraised to be part of institutions, and located within multiple historical and contemporary systems (including archives), a crip provenance builds a political, contextual, and expansive lens to illuminate the many assemblages that *could* be represented in archival description, while acknowledging that description can never be ‘complete’.

This chapter is intended to be an epistemological starting point to politicize archives for both archivists and users through an intersectional lens and to prompt reflection around positionality, systems, history, alternative understandings, and erasure. As archivists, we are responsible for not only the preservation of material but our interventions on how that material is used, understood, or complicated. Although it only addresses a few archival concepts, applying feminist disability studies broadly to build off of previous archival theory, I hope this chapter initiates future theoretical and applied change within archives. I wonder where this model might fall short or work against marginalized people when put into practice. And I wonder how this

model, and critical theory in general, might affect the ways archivists relate to their profession.[99] By politicizing and expanding upon archival concepts through this model, do we inevitably make archival work impossible? Or does offering a model to open up the problematic aspects of archival processes imply that colonialist and authoritative archives can ultimately be recuperated and/or appropriated? We, as archivists, can simultaneously understand the discrimination, oppression, and inequity baked into such systems, while recognizing that not every individual is oppressed or privileged in the same ways, identifies with their marginality, and/or desires the same outcome. My aim for this project is a generous one: not only to politicize archives and archival processes but also to open up a plural, relational, and flexible understanding of individual experiences and archival power.

Moreover, this chapter lays the foundation to expand what we consider related to a record or Chapter Five (the following chapter). As this framework advocates for the inclusion of that which may not be obviously considered as part of a record, it opens up space to think about disability in history when there is no evidence. Archival assemblages initiate thinking expansively about the systems that produce and impact records and allow for a connection of the S BLACK bag's history to parallel and intertwined settler colonial projects of eugenics and ableism. This approach therefore serves to identify histories of disability and ableism even when they may not be readily apparent in records. Thus the following chapter takes up such expansive lenses to trace the politics of materiality within archives. Just as Kurzman traces his prosthetic leg's material to military technology, so too can an archivist research a material's alternative uses and think through how to represent these expansive power dynamics and ableist histories

[99] Michelle Caswell et al., "'To Be Able to Imagine Otherwise': Community Archives and the Importance of Representation," *Archives and Records* 38, no. 1 (January 2, 2017): 5–26, https://doi.org/10.1080/23257962.2016.1260445.

that may not be immediately conspicuous. In building towards a crip provenance, which expansively contextualizes records that are simplified, incomplete, or dispersed, archival assemblages initiate an illumination of systems—and their representation in language—which orient not only towards the past, but also expansively outward and towards the future.

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Chapter Five: Materials
Chemical Assemblages: Locating Disability in History & the Materiality of Labor

Introduction

Working in archives is risky—when spending time with materials kept, organized, and preserved for future use, one becomes aware of the potency not only of records' representations of history (and violence documented, erased, or misrepresented) but also of the materiality of records, the toxins used to construct or preserve the materials themselves. Carolyn Steedman, in her book *Dust: The Archive and Cultural History*, addresses the corporeal relation to archival materiality, how one working within archives breathes in "the dust of the workers who made the papers and parchments; the dust of the animals who provided the skins for their leather bindings,"[1] not to mention anthrax, the spores of which "could come through the whole leather-making process unscathed."[2] Working off of Steedman, Zeb Tortorici thinks through how we 'consume' the physical flotsam of archival material, *metaphorically* by bearing witness to or "digesting the past" through records and also *literally* by inhaling the dust, chemicals, or fumes embedded in or emanating from archival materials.

While researchers, archivists, museum workers and those handling records and materials are exposed to substances that may be detrimental to their health, archival materials themselves—either constructed from or preserved with toxic materials—remain at the center of concern of the effects of dust, chemicals, glues, and other toxic substances. Tortorici points out

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[1] Carolyn Steedman, *Dust: The Archive and Cultural History* (New Brunswick, N.J: Rutgers University Press, 2002)., p. 27

[2] Carolyn Steedman, *Dust: The Archive and Cultural History* (New Brunswick, N.J: Rutgers University Press, 2002), 25

that "Especially in the nineteenth century… historians and archivists were constantly exposed to early printed books, old documents, leather bindings, glues, adhesives, parchments, and vellums (which were often laden with toxic chemicals and tanning agents)."[3] And these substances continue to affect archivists and those working in archives in the present day. He continues, "Even today, as anyone (like myself) who has suffered from itchy eyes, runny nose, and headaches in the archives knows, the mold, spores, dust, and airborne fragments of early modern books and manuscripts have an uncanny ability to produce severe allergic reactions in some scholars, archivists, and workers who breathe them in."[4] However as historian, Peter M. McLellan and allergist, Gordon P. Baker critique, "To date, it has been of public concern that only the records themselves do not become damaged by the dust."[5] Given that toxins have been and continue to be used in archives and museums—and although freezing and anoxia have replaced some of their uses, chemical residues remain—how might we begin to unpack the mechanism of power laden within their use?

As the third facet in building towards a crip provenance, this chapter turns to the *materials* of archives and museums in order to illuminate an expanded constellation of politics connected to disability. Kafer, in building a political/relational model of disability—a central model to building a crip provenance—emphasizes materiality. She illustrates how disability is deeply intertwined with power and politics through materiality by using Steven Kurzman's complication of being labeled a "cyborg" because of his prosthetic leg. Kurzman states:

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[3] Zeb Tortorici, "Visceral Archives of the Body Consuming the Dead, Digesting the Divine," *GLQ: A Journal of Lesbian and Gay Studies* 20, no. 4 (January 1, 2014): 407–37, https://doi.org/10.1215/10642684-2721375, 410.

[4] Zeb Tortorici, "Visceral Archives of the Body Consuming the Dead, Digesting the Divine," *GLQ: A Journal of Lesbian and Gay Studies* 20, no. 4 (January 1, 2014): 407–37, https://doi.org/10.1215/10642684-2721375, 410.

[5] Peter M. McLellan and Gordon P. Baker, "Incidence of Allergy in Archival Work," *The American Archivist* 28, no. 4 (1965): 581–84, 582.

> "if I am to be interpellated as a cyborg, it is because my leg cost $11,000 and my HMO paid for it; because I had to get a job to get the health insurance; because I stand and walk with the irony that the materials and design of my leg are based in the same military technology which has blown the limbs of so many other young men; because the shock absorber in my foot was manufactured by a company which makes shock absorbers for bicycles and motorcycles, and can be read as a product of the post–Cold War explosion of increasingly engineered sports equipment and prostheses; and because the man who built my leg struggles to hold onto his small business in a field rapidly becoming vertically integrated and corporatized. I am not a cyborg simply because I wear an artificial limb."[6]

Kafer reflects, "recognizing that our bodies are not separate from our political practices; neither assistive technologies nor our uses of them are ahistorical or apolitical."[7] She continues, "In tracing this prosthetic history, Kurzman recognizes his leg and the cyborg figure as political; his relationship to both, the prosthetic and the cyborg, is a political relationship, one embedded in larger histories, rhetorics, and economies."[8] Just as thinking about the materials used in Kurrzmas' prosthetic leg lead to understanding an assemblage of power and politics, so too can the materials used in military technology be traced back to prosthetics and disability.

Likewise, in building a crip provenance, attending to the politics and expansive materiality of records and the chemicals used to preserve or maintain them can provide, as I will

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[6] Steven L. Kurzman, "Presence and Prosthesis: A Response to Nelson and Wright," *Cultural Anthropology* 16, no. 3 (2001): 374–87, 394.

[7] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013), 120.

[8] Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington Indianapolis: Indiana University Press, 2013),121.

show, a mode of thinking about disability in history when there's little or no evidence. Specifically, in building a crip provenance, a disability studies lens helps me locate a largely unspoken dynamic and identify discourses around disability: how museums are debilitating and disabling their workers in order to preserve their collections. This chapter uses historical methods to address records as well as other histories that archives may not explicitly contain. It shows that crip provenance, a framework for expanding what is considered as part of a record by adding context, has a broad scope and can not only function as a way for complicating records that contain disabled people but also be a lens for detecting disability when it is absent.

By tracing the archival, museum, and alternative uses of *naphthalene*, one chemical used for the preservation of materials in the Field Museum, this chapter illuminates how a disability studies lens allows us to talk about disability and ableism when there is little or no obvious evidence of disability in history. Naphthalene has long been used as a fumigant in natural history museums as a preservation technique to protect anthropological collections, such as textiles and fabrics, as well as in biological collections, such as pinned insects and animal skin collections. However, as I will demonstrate, naphthalene is entangled within complex networks of power, bound up within different histories, practices, and materials. Natural history museums such as the Field Museum serve as a primary case study as they provide a clear example of not only how institutions are built on colonial legacies but also how, even when some aspects of colonial power are addressed within institutions, there are also more subtle processes that need confronting. Unlike the more conspicuous examples of disability in this history—the pygmy people in Chapter One and the circular in Chapter Four—where disabled people are represented, this chapter demonstrates how an attention to systems can expose disability's relationship with the history of the Field Museum even without explicit archival documentation. By focusing on

the widespread use of naphthalene, this chapter thinks broadly about the politics of this chemical. Specifically, with a focus on the embodied experience of exposure—of those who may come into contact with chemicals, poisons, and other irritants by means of their work—this chapter aims to highlight an imbalance of power, as preservation often comes at the expense of those working with toxins for the benefit of those who hold power. By locating chemical exposure in feminized roles of work, I simultaneously acknowledge how archival practices oppress those whose objects are contained within archives and museums as well as those that work within them.

This chapter links the museum and archival worlds by drawing many parallels, overlaps, and entanglements, but in no way implies that all claims I make always apply to both. Christina Riggs, for example, highlights some overlaps between archives and museums, "They share a history rooted in the knowledge-producing institutions of imperialism, founded in the certainties of positivism and weighed down by the need to organize vast quantities of raw data in myriad forms."[9] Joan M. Schwartz remarks on the "important parallels between museums and archives as 'memory institutions,' as both the institution and the documents they preserve "have been created by a will, for a purpose, to convey a message to an audience."[10] In this dissertation, I have used a broad definition of a record, as "evidence of an activity,"[11] so that museum materials are also considered records. With this in mind, I also connect the labor of processing museum collections with archival labor, as both involve organizing, describing, and processing of records for future use. By connecting archives and museums, I hope this chapter can contribute to each

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[9] Christina Riggs, "The Body in the Box: Archiving the Egyptian Mummy," *Archival Science*, July 5, 2016, 1–26, doi:10.1007/s10502-016-9266-8.

[10] Joan M. Schwartz, "'We Make Our Tools and Our Tools Make Us': Lessons from Photographs for the Practice, Politics, and Poetics of Diplomatics," *Archivaria* 40, no. 0 (January 1, 1995), https://archivaria.ca/index.php/archivaria/article/view/12096.

[11] Geoffrey Yeo, "Concepts of Record (1): Evidence, Information, and Persistent Representations," *The American Archivist* 70, no. 2 (2007): 315–43.

type of institution through drawing on how, as Joan M. Schwartz and Terry Cook state, "Parallels between museums and archives are obvious, and instructive," as they both "embody and shape public perceptions of what is valuable and important."[12] Throughout this chapter, I acknowledge that museum and archival practices have evolved and continue to change to be more just to the communities who have been negatively impacted by them. My aim for this chapter is not to make claims that they haven't, but instead show how by tracing one chemical, we can connect museum practices to disability (or disabling factors) which are embedded within some (not all) museum values, as naphthalene has remained in use in the Field Museum today.

To do this, I will first build off the previous chapter and utilize *archival assemblages* to locate multiple underlying systems that allow for me to critically examine the *subtleties* of disability in history. I will first historically trace the use of naphthalene and other chemicals within museums and archives. Then, I will expand my critical lens by illuminating how an attention to materiality can draw out a complex picture of a chemical's use, connected to multiple spaces, people, and disabilities. By focusing on the history, alternative uses, and impacts of naphthalene, I will demonstrate how an attention to materials allows for expansive telling of disability and ableism in history where there is little or no evidence.

Many scholars have noted how archives, through sustaining a guise of neutrality, can be embedded with "layers of meaning, layers [of power] which become naturalized, internalized, and unquestioned,"[13] and can perpetuate power relations. Continuing to center this work at the intersection of archival studies, feminist disability studies, and the history of science allows me

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[12] Joan M. Schwartz and Terry Cook, "Archives, Records, and Power: The Making of Modern Memory," *Archival Science* 2, no. 1–2 (March 1, 2002): 1–19, https://doi.org/10.1007/BF02435628, 2; Susan M. Pearce, *MUSEUMS, OBJECTS, AND COLLECTIONS* (Washington, D.C: Smithsonian Books, 1993), 89.

[13] Joan M. Schwartz and Terry Cook, "Archives, Records, and Power: The Making of Modern Memory," *Archival Science* 2, no. 1–2 (March 1, 2002): 1–19, https://doi.org/10.1007/BF02435628, 18.

to interrogate the debilitating effects of naphthalene as well as to connect it's use to other uses in a politicized assemblage of feminized labor. This is in no way an exhaustive history of the chemical naphthalene nor its full history of use in the Field Museum, however, by showing a few points on the constellation, or a few branches of the power and politics of a single chemical used in museums and archives, this chapter aims to demonstrate how a crip provenance can extend broadly to identify a method of talking about disability in history as well as how legacies of ableism and colonialism are historically interwoven.

Chemical Histories & Institutional Foundations

Broadly speaking, museum preservation techniques are often posited as methods that act against "agents of deterioration." Carolyn L. Rose and Catharine A. Hawks expand the dominant agents of deterioration in natural history collections to include "direct physical forces; thieves, vandals, and displacers; fire; water; pests; contaminants; radiation [from light damage]; incorrect temperatures; and incorrect relative humidity."[14] Many chemicals have frequently been the mechanism of preservation in museums against specific threats as they can halt or slow many of the agents of deterioration, such as pests or mold. For example museums have been preserving specimens, such as insect larvae or amphibians, by injecting them with and storing them in liquids such as ethanol or formaldehyde, which "stabilize[s] the specimen; keep[s] it in lifelike appearance and form; protect[s] it from autolysis, agents of decay, and dehydration; and minimize[s] shrinkage and swelling."[15] And methyl bromide, for example, has been used to

[14] Carolyn L. Rose and Catharine A. Hawks, "A Preventive Conservation Approach to the Storage of Collections," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 3.

[15] John E. Simmons, "Storage in Fluid Preservatives," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 161.

preserve and prevent decay in paper materials[16] as well as to fumigate collections against pest infestation.[17] Arsenic and mercuric chloride, other extremely toxic substances, were used in early dry specimen preservation.[18]

Naphthalene, situated within these foundational pedagogies of natural history museums, was developed and found to be an effective chemical used in preservation. During the early nineteenth century, chemists identified naphthalene as a substance that could be derived from coal tar.[19] John Kidd described the processes used to distill multiple substances from coal tar: an "aqueous product... [an] oily fluid... [a] white concrete substance... [and a] yellow farina."[20] Kidd proposed that the white concrete substance, "characterized by its odour, which is faintly aromatic, and not unlike that of the narcissus and some other fragrant flowers… [and] readily diffused through the surrounding atmosphere to the distance of several feet, and obstinately

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[16] Spiros Zervos and Irene Alexopoulou, "Paper Conservation Methods: A Literature Review," *Cellulose* 22, no. 5 (October 1, 2015): 2859–97, doi:10.1007/s10570-015-0699-7.

[17] Vinod Daniel, "Storage in Low-Oxygen Environments," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995),150.

[18] Catharine A. Hawks and S.L. Williams, "Arsenic in Natural History Collections," *Leather Conservation News.* 2 (Spring 1986): 1–4.

[19] Heinz-Gerhard Franck and Jürgen W. Stadelhofer, *Industrial Aromatic Chemistry: Raw Materials · Processes · Products* (Berlin Heidelberg: Springer-Verlag, 1988), //www.springer.com/us/book/9783642734342, 298; Thomas Thomson, Richard Phillips, and Edward William Brayley, *The Annals of Philosophy* (Baldwin, Cradock, and Joy., 1820)

[20] John Kidd, "XVI. Observations on Naphthaline, a Peculiar Substance Resembling a Concrete Essential Oil, Which Is Apparently Produced during the Decomposition of Coal Tar, by Exposure to a Red Heat," *Philosophical Transactions of the Royal Society of London* 111 (January 1, 1821): 209–21, https://doi.org/10.1098/rstl.1821.0017, 213-19.

adheres for a long time to any substance to which it has been communicated,"[21] be called "naphthaline" [sic].[22]

As the naphthalene's properties, particularly its pungent odor, were further investigated in the nineteenth century, it was taken up as a fumigant and pesticide within natural history museums. In 1885, John B. Smith, was one curator who proposed naphthalene as "a perfect remedy" against many pests for entomological collections if used in tandem with "tight boxes and a free use of chloroform or Bisulphide of Carbon."[23] Shortly thereafter, head curator of the Anthropology Department of the Smithsonian Museum, Walter Hough suggested naphthalene, mixed with alcohol and other chemicals, as a solution to protect "woodwork, basketry, textiles, botanical specimens, etc.," from 'destructive' pests if dipped in, sprayed or painted with the solution.[24]

As preservation is operationalized against agents of deterioration in museums, naphthalene is specifically aimed at deterring insect pests from damaging biological material in many natural history museums, including the Field Museum. Unlike formaldehyde and ethanol, iconic liquids used to 'pickle' specimens in jars, naphthalene is used in dry collections to keep

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[21] John Kidd, "XVI. Observations on Naphthaline, a Peculiar Substance Resembling a Concrete Essential Oil, Which Is Apparently Produced during the Decomposition of Coal Tar, by Exposure to a Red Heat," *Philosophical Transactions of the Royal Society of London* 111 (January 1, 1821): 209–21, https://doi.org/10.1098/rstl.1821.0017, 215.

[22] John Kidd, "XVI. Observations on Naphthaline, a Peculiar Substance Resembling a Concrete Essential Oil, Which Is Apparently Produced during the Decomposition of Coal Tar, by Exposure to a Red Heat," *Philosophical Transactions of the Royal Society of London* 111 (January 1, 1821): 209–21, https://doi.org/10.1098/rstl.1821.0017, 221.

[23] Entomological Society of Washington and John B. Smith, "Some Observations on Museum Pests," in *Proceedings of the Entomological Society of Washington* (Published by the Society, 1886), http://archive.org/details/proceedingsento07washgoog, 114-15.

[24] Walter Hough, "The Preservation of Museum Specimens from Insects and the Effects of Dampness," in *Annual Report of the Board of Regents of the Smithsonian Institution for the Year Ending June 30, 1887*, ed. United States National Museum, Report of the United States National Museum (Washington, D.C: U.S. Government Printing Office, 1889), 549–58.

insects from entering collections and destroying or damaging specimens. Wendy Jessup describes:

> "Inuit parkas have been denuded by odd beetle (*Thylodrias contractus*) larvae. Webbing clothes moth (*Tineola bisselliella*) larvae were observed to have chewed the surface of a boa constrictor skin prepared with sodium chloride and to have incorporated the snakeskin scales and the salt crystals into their pupal cases. Subterranean termites have built their shelter tubes through cracks in a concrete floor and then moved up into metal cabinets housing herbarium, sheets… Mice have urinated and defecated on turtle specimens, chewed feathers and baskets, and shredded textiles for nesting materials."[25]

Naphthalene's toxic properties were found to be successful in many types of collections—Indigenous materials made from organic components, many types of skin collections, botanical collections, and dried insect collections —to deter many types of 'pests'.[26]

The use of naphthalene has continued within natural history museum collections today. Writing in 2015, John Thompson notes, "Many museums make use of deterrents in the form of chemicals in the storage drawers. Such chemicals have included DDT, p-dichlorobenzene [PDB] and naphthalene. Only the latter is now recommended."[27] Martyn J. Linnie remarks that "Naphthalene is the most widely used chemical in museums in the British Isles and has also

[25] Wendy Claire Jessup, "Pest Management," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 211.

[26] Wendy Claire Jessup, "Pest Management," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 211–20.

[27] John M. A. Thompson, *Manual of Curatorship: A Guide to Museum Practice* (Routledge, 2015), 445.

widespread use worldwide."[28] Naphthalene, a slightly less toxic option in comparison to arsenic and mercury, became a primary pesticide in natural history museums. Makos and Hawks note in 2014 that "Fortunately, use of many pesticide chemicals has ceased in U.S. museums. However, use of PDB and naphthalene (both potential carcinogens) continues, largely because of their widespread availability in this country."[29] Although its use has been reduced in the past decade due to its carcinogenic effects,[30] it is still used to this day within many natural history collections, such as the Field Museum and the Smithsonian National Museum of Natural History.[31]

During my many years working at the Field Museum as well as during this historical and archival research, I was exposed to the vastness of its use. Nearly every drawer of the museum's 4.1 million pinned insect collections has a small box of naphthalene in it. Its fragrance wafts through the insect collections, permeates the mammal skin collections, some anthropological collections, and is even present throughout museum display cases for the public's viewing. The prevalence of not only it's visual components—tiny white crystals in every drawer of pinned insects and large bags of it stored in museum closets—but also the smell that permeates the museum's hallways drew me to think of the ubiquity of its use and therefore the exposure

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[28] Martyn J. Linnie, "Pest Control in Museums," in *Care of Collections*, ed. Simon J. Knell (Psychology Press, 1994), 234–39, 235.

[29] Kathryn A. Makos and Catharine Hawks, "Collateral Damage: Unintended Consequences of Vapor-Phase Organic Pesticides, with Emphasis on p-Dichlorobenzene and Naphthalene," 2014, https://museumpests.net/conferences/museumpests-2014-conference/museumpests-2014-conference-ipm-policy-health-and-safety/.

[30] Susan Heald and Odile Madden, "Investigations into Naphthalene Mitigation on Museum Objects," 2011; Rebecca A. Kaczkowski et al., "Investigation of Residual Contamination Inside Storage Cabinets: Collection Care Benefits from an Industrial Hygiene Study," *Journal of the American Institute for Conservation* 56, no. 2 (April 3, 2017): 142–60, https://doi.org/10.1080/01971360.2017.1326242.

[31] Kathryn A. Makos and Catharine Hawks, "Collateral Damage: Unintended Consequences of Vapor-Phase Organic Pesticides, with Emphasis on p-Dichlorobenzene and Naphthalene," 2014, https://museumpests.net/conferences/museumpests-2014-conference/museumpests-2014-conference-ipm-policy-health-and-safety/.

endured by museum workers. Given naphthalene's early popularity within these institutions as well as the continuation and prevalence of its use—from the late nineteenth century to today—I was drawn to tracing the effects of its use and how it functions in service of certain ideals.

Naphthalene briefly made its way into archives and libraries for similar purposes to museums, although it was less popular as a fumigant for paper records than in natural history collections.[32] In 1924, the Archives of the Corporation of the City of London cited it as one method, used like "ortho-diclor-benzol, which is much more efficacious than naphthalene, and has peculiarly penetrating powers, causing rapid death to the grubs."[33] However, it was not as popular as the more commonly used thymol, which prevents fungal attacks on paper.[34] Considering the overlaps in museum and archival work, the prevalence of toxic preservatives and allergens in both, and the prioritization of materials over memory worker health, I'm interested in exploring these intersections to tease out the politics of naphthalene, mostly in the context of museums but that also expands to archives that use chemical treatments (not necessarily naphthalene) as well.

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[32] Norbert S. Baer and Margaret Holben Ellis, "Conservation Notes: On Thymol Fumigation," *International Journal of Museum Management and Curatorship* 7, no. 2 (June 1, 1988): 185–88, https://doi.org/10.1080/09647778809515120.

[33] C. L. Kingsford, "Calendar of Early Mayor's Court Rolls, Preserved among the Archives of the Corporation of the City of London. A. D. 1298–1307. Edited by A. H. Thomas, M.A., Clerk of the Records. Printed by Order of the Corporation under the Direction of the Library Committee. 10 × 6; Pp. Xlv + 304. Cambridge: At the University Press. 1924. 15s.," *The Antiquaries Journal* 5, no. 1 (January 1925): 100–102, https://doi.org/10.1017/S0003581500015456 - P 100; Iván Borsa, "Archives in Japan," *Journal of the Society of Archivists* 7, no. 5 (April 1, 1984): 287–94, https://doi.org/10.1080/00379818409514242; Adupa Sunil and K. Praveen Kumar, "Preservation of Library Materials: Problems and Perspective," *DESIDOC Journal of Library & Information Technology* 29, no. 3 (July 2009): 37–40.

[34] Norbert S. Baer and Margaret Holben Ellis, "Conservation Notes: On Thymol Fumigation," *International Journal of Museum Management and Curatorship* 7, no. 2 (June 1, 1988): 185–88, https://doi.org/10.1080/09647778809515120.

Expanding Chemical Assemblages: Materiality of Labor & Toxic Exposure

Considering the history of naphthalene within natural history museums, I want to expand my theoretical lens through an attention to materiality to these connected histories. The previous section provided a lens for thinking through the history of the development of naphthalene as a chemical preservative. Building on this by thinking about the politics of materiality, I want to expand this lens further as a way to talk about disability in history when there is no evidence—to draw attention to a material's alternative uses and think through how to represent these expansive power dynamics that may not be immediately conspicuous. To do this, I build on Sara Ahmed's work on queer phenomenology which "allows us to theorize how a reality is given by becoming background, that which is taken for granted." Ahmed "show[s] how phenomenology faces a certain direction, which depends on the relegation of other 'things' to the background."[35] When archival and museums processes, such as object preservation and organization, become deeply ingrained in institutions, they are accepted as "the established order, the already existing norm."[36] Teasing out the complexity of the assemblage of naphthalene is therefore crucial to understanding the knowledges that build upon one another. Chemicals, like any material, technology, or pedagogy, do not exist in isolation. Deleuze and Guattari highlight how "tools exist in relation to the interminglings they make possible or that make them possible."[37] Through an attention to what materials and practices have been institutionalized, I will show how an

[35] Sara Ahmed, *Queer Phenomenology: Orientations, Objects, Others*, First Edition edition (Durham: Duke University Press Books, 2006), 27.

[36] Samuel Weber, *Institution and Interpretation: Expanded Edition*, 1 edition (Stanford, Calif: Stanford University Press, 2002), xv.

[37] Gilles Deleuze and Felix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi, 1St Edition edition (Minneapolis: University of Minnesota Press, 1987), 90.

expansive lens around materiality allows for the centering of disability and ableism within museum and parallel histories and can draw attention to that which may be in the background.

But first, I want to acknowledge how museum practices, including those around chemical use, are changing. The recent publication of the book *Preventive Conservation: Collection Storage*, for example, demonstrates the contemporary challenging of how museum perspectives have historically been prioritized over "non-museum stakeholders."[38] In this book, Sanchita Balachandran and Kelly McHugh argue for more active and responsible stewardship to restore the social and cultural relevance of collections.[39] This work combats how museum ideals have historically overshadowed other communities' values. For example, Shauna McRanor provides a straightforward example by demonstrating how the colonization of Native materials into natural history museums represents dominant ideals while erasing others. McRanor's example of pts'aan (totem poles)—that were intended to decay and change over time—were preserved in support of institutional efforts instead of their makers' wishes.[40] McRanor argues that significance "is lost for those who believe that preservation is only attainable in sterile, climate-controlled museums… Denied their context of creation and their place on the land, *pts'aan* [totem poles] are effectively eviscerated of their archival nature and their probation power as proof of

[38] Lisa Elkin and Christopher A. Norris, *Preventive Conservation: Collection Storage* (Society for the Preservation of Natural History Collections, 2019).

[39] Sanchita Balachandran and Kelly McHugh, "Respectful and Responsible Stewardship: Maintaining and Renewing the Cultural Relevance of Museum Collections," in *Preventive Conservation: Collection Storage* (Society for the Preservation of Natural History Collections, 2019), 3–24.

[40] Shauna McRanor, "Maintaining the Reliability of Aboriginal Oral Records and Their Material Manifestations: Implications for Archival Practice," *Archivaria* 42, no. 0 (February 12, 1997), http://archivaria.ca/index.php/archivaria/article/view/12176.

action."[41] Examples such as this identify a foundational problem within preservation and colonial pedagogies, which are being challenged within museums.[42]

Furthermore, chemical exposure around Indigenous materials has also come to light. The Native American Graves Repatriation and Protection Act (NAGPRA) was updated in 1993 with CFR (Code of Federal Regulations) 10.10 stating that museums must inform recipients of repatriated materials that have been treated "with pesticides, preservatives, or other substances that represent a potential hazard to the objects or to persons handling the objects."[43] Peter T. Palmer, Matthew Martin, Gregory Wentworth, Niccolo Caldararo, Lee Davis, Shawn Kanell, and

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[41] Shauna McRanor, "Maintaining the Reliability of Aboriginal Oral Records and Their Material Manifestations: Implications for Archival Practice," *Archivaria* 42, no. 0 (February 12, 1997), http://archivaria.ca/index.php/archivaria/article/view/12176, 71.

[42] Turner H (2015) Decolonizing ethnographic documentation: a critical history of the early museum catalogs at the Smithsonian's National Museum of Natural History; Sue McKemmish, Shannon Faulkhead, and Lynette Russell, "Distrust in the Archive: Reconciling Records," *ResearchGate* 11, no. 3–4 (November 1, 2011), doi:10.1007/s10502-011-9153-2; Ann Mary Doyle, "Naming, Claiming, and (Re)Creating : Indigenous Knowledge Organization at the Cultural Interface" (University of British Columbia, 2013), https://doi.org/10.14288/1.0073667; Sandra Littletree and Cheryl A. Metoyer, "Knowledge Organization from an Indigenous Perspective: The Mashantucket Pequot Thesaurus of American Indian Terminology Project," *Cataloging & Classification Quarterly* 53, no. 5–6 (July 4, 2015): 640–57, https://doi.org/10.1080/01639374.2015.1010113; Ellen Hoobler, "'To Take Their Heritage in Their Hands': Indigenous Self-Representation and Decolonization in the Community Museums of Oaxaca, Mexico," The American Indian Quarterly 30, no. 3 (September 6, 2006): 441–60, https://doi.org/10.1353/aiq.2006.0024; Norman K. Denzin and Yvonna S. Lincoln, "Introduction: Critical Methodologies and Indigenous Inquiry," in Handbook of Critical and Indigenous Methodologies, ed. Norman K. Denzin, Yvonna S. Lincoln, and Linda Tuhiwai Smith, 1 edition (Los Angeles London New Delhi Singapore: SAGE Publications, Inc, 2008), 1–20; Shannon Faulkhead, "Connecting through Records: Narratives of Koorie Victoria," Archives and Manuscripts 37, no. 2 (November 2009): 60; Sue McKemmish, Shannon Faulkhead, and Lynette Russell, "Distrust in the Archive: Reconciling Records," Archival Science 11, no. 3 (November 1, 2011): 211–39, https://doi.org/10.1007/s10502-011-9153-2; Amy Lonetree, Decolonizing Museums: Representing Native America in National and Tribal Museums (Univ of North Carolina Press, 2012); Linda Tuhiwai Smith, Decolonizing Methodologies: Research and Indigenous Peoples, 2 edition (London: Zed Books, 2012); Marisa Elena Duarte and Miranda Belarde-Lewis, "Imagining: Creating Spaces for Indigenous Ontologies," Cataloging & Classification Quarterly 53, no. 5–6 (July 4, 2015): 677–702, https://doi.org/10.1080/01639374.2015.1018396; Sandra Littletree and Cheryl A. Metoyer, "Knowledge Organization from an Indigenous Perspective: The Mashantucket Pequot Thesaurus of American Indian Terminology Project," Cataloging & Classification Quarterly 53, no. 5–6 (July 4, 2015): 640–57, https://doi.org/10.1080/01639374.2015.1010113; Bryony Onciul, Museums, Heritage and Indigenous Voice: Decolonizing Engagement (Routledge, 2015); Hannah Turner, "Decolonizing Ethnographic Documentation: A Critical History of the Early Museum Catalogs at the Smithsonian's National Museum of Natural History," Cataloging & Classification Quarterly 53, no. 5–6 (July 4, 2015): 658–76, https://doi.org/10.1080/0163.

[43] "43 CFR § 10.10 - Repatriation.," Legal Information Institute, accessed July 8, 2020, https://www.law.cornell.edu/cfr/text/43/10.10.

David Hostler detail how mercury, arsenic and other pesticides are present in materials that were repatriated to the Hupa tribe.[44] And Micah Loma'omvaya addresses how repatriating contaminated materials need to be addressed uniquely within different tribes.[45] Due to the use of chemicals on Indigenous materials within natural history museums and other cultural institutions, it's no wonder that there has been push back around the effects of chemical preservation on the people to whom materials belong. S. Jordan Simms and John D. McIntyre state, "Whatever the original intent, these practices [of conservation and cultural stewardship], in their aggregate effect, have significantly undermined repatriation efforts currently underway across a range of communities."[46] Through also addressing the harmful impacts on Native communities and the ways in which museum preservation practices are upheld or maintained to the detriment of the communities to which these objects belong, we can also understand how such practices *can* preserve—literally and figuratively—colonial ideals. These works illustrate the immediacy with which chemicals used in preservation are being addressed, the ways in which power is bound up within contemporary preservation techniques, and how the politics of chemical preservation expand outside of an institution's walls.

While museum practices have been challenged and preservation practices are changing, I am interested in the ways in which historical values may be sustained in more inconspicuous ways. Although these practices may be updated—multiple perspectives are being considered,

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[44] Peter T. Palmer et al., "Analysis of Pesticide Residues on Museum Objects Repatriated to the Hupa Tribe of California," *Environmental Science & Technology* 37, no. 6 (March 1, 2003): 1083–88, https://doi.org/10.1021/es026235n.

[45] Micah Loma'omvaya, "NAGPRA Artifact Repatriation and Pesticides Contamination: Human Exposure to Pesticide Residue Through Hopi Cultural Use," ed. Society for the Preservation of Natural History Collections, *Collection Forum* 16, no. 1–2 (Summer 2001).

[46] S. Jordan Simms and John D. McIntyre, "Toxic Representations: Museum Collections and the Contamination of Native Culture," *The Canadian Journal of Native Studies* 34, no. 1 (January 1, 2014): 151.

chemicals are being replaced with other solutions, materials are being repatriated—I want to recognize that museums might be slow to implement change and some values and practices may persist. And an attention to naphthalene can help me illustrate just this. In the canonical text, *Storage of Natural History Collections*, Rose and Hawks state that "any alteration of a specimen or object has the potential to adversely affect the utility of that specimen or object for the *purposes for which it was collected*."[47] Chemical preservation, for Rose and Hawks, functions for the sustaining of the underlying pedagogies, to preserve and maintain a specimen for its *original purpose* of serving western knowledges. While this text has been superseded by texts such as *Preventive Conservation*,[48] I'm curious about how we might surface ways in which these values are sustained and how they might show up today.

To discuss such underlying values, I center the history of the use of chemical preservation within museums and focus on the implications for the people who still experience the repercussions of the ubiquitous use of chemicals in museums. Through an analysis of who is exposed to chemicals, their potential harms, and to whose benefit, the politics of prioritization of historical ideologies of preservation—what Ahmed describes as "when things become institutional, they recede."[49]—can resurface. Naphthalene is widely used in natural history museums, as I've stated above, it is used not only within Native materials and anthropological collections, but it is also a dominant chemical within biological collections, such as pinned insects and mammal furs—collections that may not demonstrate immediate connections to

[47] Carolyn L. Rose and Catharine A. Hawks, "A Preventive Conservation Approach to the Storage of Collections," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 2, emphasis mine.

[48] Lisa Elkin and Christopher A. Norris, *Preventive Conservation: Collection Storage* (Society for the Preservation of Natural History Collections, 2019).

[49] Sara Ahmed, *On Being Included: Racism and Diversity in Institutional Life* (Durham u.a.: Duke University Press Books, 2012), 21.

colonialism. While critical attention has begun to be paid to the implications of pesticides use on Indigenous communities, I think alongside such critiques to also grapple with the politics of materiality even when those politics are less conspicuous. Therefore my first level of analysis turns toward those working within natural history museums. At the Field Museum, like many natural history museums, those who are exposed to naphthalene most often are those, such as collections workers or conservators, interns, volunteers and others who work on projects related to: curating and updating parts of collections, databasing or digitizing materials, or processing materials for research loans. While I center the labor of those working within archives and museums, it is also important to recognize that collections workers and conservators participate in oppressive systems and that they also may be oppressed by those systems.[50]

The labor of handling, processing, and preserving collections is, as I will show, historically feminized work. The work of the collections workers and conservators—people working within the collections of natural history museums—is closely aligned with archival labor; the tasks that collections workers often perform, for example preserving, organizing, and cataloging, are tasks that align and intersect with archival work. Michelle Caswell and Terry Cook have interrogated the value placed on the role of the archivist as it is a feminized profession and undervalued as a perspective on archival material.[51] Caswell contends that "the construction of archival labor as a feminine service industry and archival studies (if it is ever

[50] Terry Cook, "The Archive(s) Is a Foreign Country: Historians, Archivists, and the Changing Archival Landscape," *The American Archivist* 74, no. 2 (September 1, 2011): 600–632, doi:10.17723/aarc.74.2.xm04573740262424.

[51] Michelle Caswell, "'The Archive' is Not An Archives: Acknowledging the Intellectual Contributions of Archival Studies[i]," *Reconstruction: Studies in Contemporary Culture* 16, no. 1, accessed October 3, 2016, http://reconstruction.eserver.org/Issues/161/Caswell.shtml.

even acknowledged as existing) as imparting merely practical how-to skills."[52] This pervasive attitude, such that Cook and Caswell demonstrate, has a long history and is ingrained that the majority of archivists reportedly identify as women.[53] Emphasizing the feminization of the profession, Cook highlights that "until the 1980s, at least in Canada, archivists were often termed the 'handmaidens of historians.'"[54] And Jessica Lap, taking up this metaphor of feminized archival labor, traces "the ways in which the archive and those working within it have been coded feminine through a language of sexual power and dominance," such as "the archival worker and the archive as a feminized space appear often in detective and police shows" and in many pop culture representations.[55] She expands on archival work: "We also know that in the workplace it is women and other marginalized workers who take on the most uncompensated service labour and emotional labour; an issue compounded by intersections of race, class, sexuality, gender and ability."[56]

Likewise, within museums, gender discrepancies have been illuminated in different facets: from the ways in which gendered labor is depicted in museums displays,[57] the gender

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[52] Michelle Caswell, "'The Archive' is Not An Archives: Acknowledging the Intellectual Contributions of Archival Studies[i]," *Reconstruction: Studies in Contemporary Culture* 16, no. 1, accessed October 3, 2016, http://reconstruction.eserver.org/Issues/161/Caswell.shtml.

[53] The 2017 Salary Survey reported that 84.3 % of archivists self-identified as female. Society of American Archivists, A*Census (2006): http://www2.archivists.org/. OR http://www2.archivists.org/sites/all/files/ACensus-Part3-Expanded.pdf; Robin H. Israel and Jodi Reeves Eyre, "The 2017 WArS/SAA Salary Survey: Initial Results and Analysis," Society of American Archivists, Women Archivists Section, 2017, 7.

[54] Terry Cook, "The Archive(s) Is a Foreign Country: Historians, Archivists, and the Changing Archival Landscape," *The American Archivist* 74, no. 2 (September 1, 2011): 600–632, doi:10.17723/aarc.74.2.xm04573740262424.

[55] Jessica M. Lapp, "'Handmaidens of History': Speculating on the Feminization of Archival Work," *Archival Science* 19, no. 3 (September 1, 2019): 215–34, https://doi.org/10.1007/s10502-019-09319-7, 217, 218.

[56] Jessica M. Lapp, "'Handmaidens of History': Speculating on the Feminization of Archival Work," *Archival Science* 19, no. 3 (September 1, 2019): 215–34, https://doi.org/10.1007/s10502-019-09319-7, 228.

[57] Gaby Porter, "Gender Bias: Representations of Work in History Museums," *Continuum* 3, no. 1 (January 1, 1990): 70–83, https://doi.org/10.1080/10304319009388150.

biases in the display of materials,[58] to the ways in which educational differences in STEM education may deter women from pursuing higher education, while museum curator positions tend to require doctoral degrees.[59] Within the field of conservation, Suzanne L. Davis identifies a significant pay gap between men and women, where "men earned about 21% more than women" in the field. Yet, through analyzing data around gender from the American Institute for Conservation, Davis found "a slow yet consistent decline in the number of men" resulting in only 18% of respondents identifying as men in 2018.[60] Marjorie Schwarzer argues that as much as museum roles have diversified in the inclusion of women, with more access to positions of authority, as well as how feminist discourse has affected roles such as exhibition practices, visitor services, and personnel relations, women's presence in governing bodies is still not palpable.[61] She states, "Despite women's presence, men dominate museums in two critical areas: power and money. Men hold sway over boards of directors, major donor lists, and pay scales. They occupy 53 percent of executive director positions in small and mid-sized museums, and 75 percent of CEO seats at the nation's largest and best-funded institutions."[62] Historically, Cook notes, whereas men tended to dominate roles such as historians, naturalists, and scientists,

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[58] Rebecca Machin, "Gender Representation in the Natural History Galleries at the Manchester Museum," *Museum and Society* 6, no. 1 (2008): 54–67; Judy Diamond, "Sex Differences in Science Museums: A Review," *Curator: The Museum Journal* 37, no. 1 (March 1, 1994): 17–24, https://doi.org/10.1111/j.2151-6952.1994.tb01003.x.

[59] "Statistics: State of Girls and Women in STEM," National Girls Collaborative Project, accessed August 15, 2018, http://ngcproject.org/statistics.

[60] Membership Designation Working Group. 2018. "2018 Member Designation Survey: Preliminary Report." American Institute for the Conservation of Historic and Artistic Works. https://higherlogicdownload.s3-external-1.amazonaws.com/CONSERVATIONUS/Member%20Designation%20Survey%20-%20Preliminary%20Report1.pdf?AWSAccessKeyId=AKIAJH5D4I4FWRALBOUA&Expires=1535548701&Signature=k%2FeKs2LxETfx0AATr5RkfnfLZ3c%3D. (AIC membership required to view document).

[61] Marjorie Schwarzer, "Women in the Temple: Gender and Leadership in Museums," in *Gender, Sexuality and Museums: A Routledge Reader*, ed. Amy K. Levin, 1 edition (Routledge, 2010), 16–27.

[62] Marjorie Schwarzer, "Women in the Temple: Gender and Leadership in Museums," in *Gender, Sexuality and Museums: A Routledge Reader*, ed. Amy K. Levin, 1 edition (Routledge, 2010), 16–27.

women came to be relegated to particular types of labor, such that in archives, nursing, and domestic work.[63] Natural history museums exemplify such divides, as they are deeply intertwined with the history of science and the role of the naturalist, which has been a male-dominated profession. Today, curators at the Field Museum, like in many museums, tend to be predominantly men: over the past 10 years, the Field has had 36 curators, only 7 of which were identified as women.[64]

By drawing connections between archival and museum conservation work, both of which can be understood as feminized labor, I in no way mean to apply that all archivists or conservators/collections workers are women. And I am less concerned with men/women binaries, but use them to illuminate feminized positions within labor and how those who have historically had less power tend to inhabit such feminized roles. What this connection does do, however, is not only highlight historical gender gaps within these fields but also, importantly, underscore the value placed on this type of work—work that includes organizing, describing, and maintaining collections of materials, work that can include (and does in the case of the Field) exposure to toxic substances. Museum gender gaps aside, which tend to reinforce (white) men in positions of more authority and women both in lower positions as well as at lower pay rates,[65]

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[63] Terry Cook, "The Archive(s) Is a Foreign Country: Historians, Archivists, and the Changing Archival Landscape," *The American Archivist* 74, no. 2 (September 1, 2011): 600–632, doi:10.17723/aarc.74.2.xm04573740262424.

[64] Craig Merriman, "Museum Stats," February 14, 2017.

[65] gov.uk, "Natural History Museum Gender Pay Gap Data / 2017-18," gov.uk: Report your gender pay gap data, accessed August 15, 2018, https://gender-pay-gap.service.gov.uk/viewing/employer-%2cF4ZlAFXAjqeLfjjLhjjl3g!!/report-2017; Veronica Treviño et al., "The Ongoing Gender Gap in Art Museum Directorships" (Association of Art Museum Directors, March 22, 2017), https://aamd.org/sites/default/files/document/AAMD%20NCAR%20Gender%20Gap%202017.pdf; Joan Baldwin, "The Question of Gender: The 'Unseen' Problem in Museum Workplaces – American Alliance of Museums," accessed August 15, 2018, https://www.aam-us.org/2017/08/28/the-question-of-gender-the-unseen-problem-in-museum-workplaces/; Marjorie Schwarzer, "Women in the Temple: Gender and Leadership in Museums," in *Gender, Sexuality and Museums: A Routledge Reader*, ed. Amy K. Levin, 1 edition (Routledge, 2010), 16–27.

Davis poignantly describes how the "widespread cultural devaluation of 'women's work' means that it is not great for anyone – male or female – to work in such a field; wages are lower and opportunities fewer for both sexes"[66] So while curators often collect materials for museums collections, they also heavily depend on well-organized collections to incorporate new material as well as to study previously collected specimens. The feminized labor of collections work, deeply tied to the organization, preservation and maintenance of collections, tends to be in service of a historically masculinized profession.[67]

Expanding further—outside of museums and archives—an assemblage approach to records can draw further connections to the politics of naphthalene. Paralleling naphthalene's use in homes alongside its use in museums is a way to further interrogate the ways in which power and politics extend beyond a singular instance and highlight how power is embedded within multiple systems that mirror one another. Naphthalene's popularity arose from its ability to deter moths and other insects from eating/damaging objects made from biological material, such as wool, fur, cotton, and other natural fibers. Thus, during the 20th century, naphthalene mothballs became a common household item to fumigate clothing, blankets, and other materials within homes. Naphthalene also came to have a wide array of uses around the home, as Chunrong Jia and Stuart Batterman point out, it was used "as a fumigant to repel animals and insects in closets, attics, soils (including gardens), and other applications, and also as a deodorizer in diaper pails and toilets. Outdoors, it is used to control nuisance vertebrate pests (snakes, squirrels, rats,

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[66] Suzanne L. Davis, "Understanding and Improving Gender Equity in Conservation," *Journal of the American Institute for Conservation* 58, no. 4 (October 2, 2019): 202–16, https://doi.org/10.1080/01971360.2019.1612723.

[67] Terry Cook, "The Archive(s) Is a Foreign Country: Historians, Archivists, and the Changing Archival Landscape," *The American Archivist* 74, no. 2 (September 1, 2011): 600–632, doi:10.17723/aarc.74.2.xm04573740262424.

rabbits, bats, etc.) around garden and building peripheries."[68] Moreover, the chemical is often the main ingredient in toilet cakes to keep toilet bowls clean,[69] and has been noted as present in many building materials.[70] Through an assemblage lens and with an attention to materiality, naphthalene can be understood broadly as embedded in multiple systems of injustice, exploitation, and exposure, which I will continue to expand on below.

Within this critique, domestic work and the ways it has been historically feminized is central. In her book investigating domestic and care work in private households of migrant women (and a decolonial analysis of the feminization of domestic labor), Encarnación Gutiérrez-Rodríguez bluntly states, "Despite the assumed *flexibilization* of gender roles and the option of paternity leave and part-time work in urban middle-class households, a perpetuation of the classical gendered division of work is kept alive. Women are still largely opting for maternity leave and part-time jobs as they principally bear the major responsibilities in regard to children and housework."[71] Other feminist activists have addressed the ways in which domestic and household work has been feminized, undervalued and underpaid, from the expectation of women to perform such labor in relation to their own homes as well as the exploitative (often colonial) systems that exploit migrant women in performing such tasks.[72]

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[68] Chunrong Jia and Stuart Batterman, "A Critical Review of Naphthalene Sources and Exposures Relevant to Indoor and Outdoor Air," *International Journal of Environmental Research and Public Health* 7, no. 7 (July 2010): 2903–39, https://doi.org/10.3390/ijerph7072903.

[69] "Naphthalene in Moth Balls and Toilet Deodorant Cakes - Fact Sheets," accessed June 9, 2017, http://www.health.nsw.gov.au/environment/factsheets/Pages/naphthalene.aspx.

[70] Chunrong Jia and Stuart Batterman, "A Critical Review of Naphthalene Sources and Exposures Relevant to Indoor and Outdoor Air," *International Journal of Environmental Research and Public Health* 7, no. 7 (July 2010): 2903–39, https://doi.org/10.3390/ijerph7072903.

[71] Encarnación Gutiérrez-Rodríguez, *Migration, Domestic Work and Affect : A Decolonial Approach on Value and the Feminization of Labor* (Routledge, 2010), https://doi.org/10.4324/9780203848661, p 1.

[72] Diane Elson, "The Economic, the Political and the Domestic: Businesses, States and Households in the Organisation of Production," *New Political Economy* 3, no. 2 (July 1, 1998): 189–208,

To note, I'm not the first to connect archival and domestic spaces. Lapp articulates the connection, as "archivists were positioned as 'caretakers' who created 'homes' for records,"[73] and even Derrida, a foundational thinker on archives, traces archives to the Greek word, "arkheion" or "a house, a domicile, an address, the residence of the superior magistrates."[74] Lapp expands, "That archival labour has historically been subsumed under the umbrella of reproductive labour is a common theme across stories of family and personal archives where women were the primary documentarians."[75] And, further drawing on the "handmaids of historians" analogy, she traces it back to the "voicelessness associated with the handmaiden, this origin story points to the root of the handmaiden's purpose: to provide reproductive labour that preserves a patrilineal provenance."[76] Connecting these two spaces within the context of their exposure to naphthalene begins to illuminate the politics of materiality as well as a connection to disability.

Through drawing parallels between domestic and museum spaces and their uses of naphthalene, I can additionally bring in disability as a central piece of the history of the Field Museum. Naphthalene's ubiquitous use in these two spaces, along with an attention to its

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https://doi.org/10.1080/13563469808406349; Isabella Bakker, "Social Reproduction and the Constitution of a Gendered Political Economy," *New Political Economy* 12, no. 4 (December 1, 2007): 541–56, https://doi.org/10.1080/13563460701661561; Encarnacion Gutierrez-Rodriguez, "Domestic Work–Affective Labor: On Feminization and the Coloniality of Labor," *Women's Studies International Forum*, Special Issue on Domestic Work between Regulation and Intimacy, 46 (September 1, 2014): 45–53, https://doi.org/10.1016/j.wsif.2014.03.005.

[73] Jessica M. Lapp, "'Handmaidens of History': Speculating on the Feminization of Archival Work," *Archival Science* 19, no. 3 (September 1, 2019): 215–34, https://doi.org/10.1007/s10502-019-09319-7, 216.

[74] Jacques Derrida, "Archive Fever: A Freudian Impression," trans. Eric Prenowitz, *Diacritics* 25, no. 2 (1995): 9–63, https://doi.org/10.2307/465144, 9.

[75] Jessica M. Lapp, "'Handmaidens of History': Speculating on the Feminization of Archival Work," *Archival Science* 19, no. 3 (September 1, 2019): 215–34, https://doi.org/10.1007/s10502-019-09319-7, 224.

[76] Jessica M. Lapp, "'Handmaidens of History': Speculating on the Feminization of Archival Work," *Archival Science* 19, no. 3 (September 1, 2019): 215–34, https://doi.org/10.1007/s10502-019-09319-7, 217.

toxicity, links these two historical tracings to disability, illness, and, more acutely, to *debility*. Debility, as Puar outlines, refers not necessarily to an explicit disability, but to bodily injury, "neoliberalism's heightened demands on bodily capacity," and "the ongoingness of structural inequality and suffering."[77] While thinking through the politics of disability alongside the debilitating symptoms of naphthalene, I want to stress that this in no way implies an idealized able bodymind as the point from which to measure difference or as an ideal. Much of the work at the intersection of disability studies and environmental justice is similarly cautious about disability as a measurement of harm as well as reliant on an ideal normate bodymind. Kelly Fritsch notes the "troubling consequences for how ableism and environmental activism come together against disability, particularly when disability is framed as an individual health problem resulting from a toxic environment."[78] Focusing on the ways in which a chemical can cause illness risks suggesting not only that disabled or sick bodies and minds are somehow 'lesser than' or should be cured but also that they were formerly 'healthy' or unexposed to any other toxin, making them the point of measurement of harm. Kim Q. Hall states "To crip sustainability means valuing disability as a source of insight about how the border between the natural and the unnatural is maintained and for whose benefit."[79] Likewise, I aim to use feminist disability studies to think through not necessarily the sick-making aspects of naphthalene, but the power that lies within who gets sick and the ways in which bodies are connected to materials, placing

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[77] Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham London: Duke University Press Books, 2017), 1.

[78] Fritsch, Kelly. "Toxic Pregnancies: Speculative Futures, Disabling Environments, and Neoliberal Biocapital." In *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, edited by Sarah Jaquette Ray and Jay Sibara, 359–80. Lincoln, NE: University of Nebraska Press, 2017, p. 365-7.

[79] Hall, Kim Q. "Cripping Sustainability, Realizing Food Justice." In *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, edited by Sarah Jaquette Ray and Jay Sibara, 422–47. Lincoln, NE: University of Nebraska Press, 2017, p.438

an emphasis on the systems that locate it in an assemblage of harm rather than on an individualized notion of disability. To associate these spaces that demand the use of naphthalene and therefore toxic exposure critically connects feminized labor as part of an assemblage which can uncover its politics.

Given the toxic properties of naphthalene as well as the way in which it vaporizes to become a fumigant—which makes it such a successful pest deterrent—it is no surprise that its ubiquitous use has come under scrutiny from those exposed to its toxic properties. Those exposed to naphthalene are at risk for many of the health concerns that come with chemical exposure, whether intentional or not.[80] It has been shown to be a carcinogen, producing tumors in lungs, damage to nose and lungs, and cloudiness of eyes after long term daily exposure.[81]

Museum workers have long been alerted to naphthalene's toxicity. Even during its early use in museum collections, in 1889 Walter Hough suggested that objects exposed to naphthalene should be accompanied by poison tags as "convenient for showing whether specimens are poisoned or not," and "be printed with a death's-head the word 'poisoned,' with a space for the date and museum number."[82] Much later, in a 1994 study of the health impacts on collections workers within museums, Linnie notes "Health-related effects associated with this substance include profuse sweating, nausea, acute kidney failure, headaches and abdominal pain."[83] Linnie

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[80] Tanveer Singh Kundra et al., "Naphthalene Poisoning Following Ingestion of Mothballs: A Case Report," *Journal of Clinical and Diagnostic Research : JCDR* 9, no. 8 (August 2015): UD01–2, https://doi.org/10.7860/JCDR/2015/15503.6274.

[81] "Public Health Statement: Naphthalene, 1-Methylnapthalene, 2-Methylnapthalene," *Agency for Toxic Substances & Disease Registry*, accessed March 23, 2017, https://www.atsdr.cdc.gov/phs/phs.asp?id=238&tid=43.

[82] Walter Hough, "The Preservation of Museum Specimens from Insects and the Effects of Dampness," in *Annual Report of the Board of Regents of the Smithsonian Institution for the Year Ending June 30, 1887*, ed. United States National Museum, Report of the United States National Museum (Washington, D.C: U.S. Government Printing Office, 1889), 557.

[83] Martyn J. Linnie, "Pest Control in Museums," in *Care of Collections*, ed. Simon J. Knell (Psychology Press, 1994), 235.

found that “thirty percent of workers associated their medical complaints with the application of pesticides and with working in close proximity to areas of pesticide usage. Paradichlorobenzene (PDB) and naphthalene being the most widely used substances were also associated with the majority of complaints particularly in relation to headaches, sore eyes, sore throat, [dizziness, chest pains, nausea] and dermatitis.”[84] Moreover, “Other incidents included the loss of consciousness in one worker caused by exposure to naphthalene, which two cases of vomiting caused by exposure to PDB and naphthalene were also reported.”[85] Similarly, Susan Heald and Odile Madden caution that “There is mounting concern about the toxicity and carcinogenicity of these substances. Conservators working with mothball-contaminated collections can experience nausea, headaches, and irritation from the odor, which can be especially strong during humidification or aqueous conservation treatments.”[86] Due to naphthalene’s toxicity, some efforts have been made to mitigate some of the toxic aspects, especially since chemicals can permeate cabinets, leaving fumes to linger long after chemicals have been removed.[87] With a close attention to the toxic properties of chemicals as well as how their effects can last beyond their immediate use, I have illustrated how those working within feminized museum labor are disproportionately exposed to the harmful effects of naphthalene.

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[84] Martyn J. Linnie, “Pest Control in Natural History Museums; A World Survey,” *Journal of Biological Curation* 1, no. 5 (1994): 52.

[85] Martyn J. Linnie, “Pest Control in Natural History Museums; A World Survey,” *Journal of Biological Curation* 1, no. 5 (1994): 52.

[86] Susan Heald and Odile Madden, “Investigations into Naphthalene Mitigation on Museum Objects,” 2011.

[87] Rebecca A. Kaczkowski et al., “Investigation of Residual Contamination Inside Storage Cabinets: Collection Care Benefits from an Industrial Hygiene Study,” *Journal of the American Institute for Conservation* 56, no. 2 (April 3, 2017): 142–60, https://doi.org/10.1080/01971360.2017.1326242.

Within domestic settings, both mothballs and deodorant cakes have been reportedly ingested by children and are, as intended, extremely poisonous.[88] A 1958 study showed a significant rise in the cases of children being poisoned from the ingestion of mothballs, either by eating them or being in homes "found to be 'reeking' of mothballs," which led to "acute hernolytic anemia" or, in some cases death.[89] A 1983 CDC report illustrates a case of a woman, "whose friends were becoming ill with symptoms of headache, nausea, and vomiting while visiting her apartment," due to her heavy use of mothballs. The report states, "The woman, her 4-year-old daughter, and seven relatives living in two other households where mothballs were extensively used, had symptoms and medical findings compatible with naphthalene exposure--headache, nausea, vomiting, abdominal pain, malaise, confusion, anemia, icterus, and renal disease."[90] These are just a few examples of the long history of exposure to naphthalene within domestic settings.[91] Naphthalene, compared to other concentrations and exposures of volatile organic compounds (VOCs), was ranked second highest of indoor emission sources as a chronic

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[88] "Public Health Statement: Naphthalene, 1-Methylnapthalene, 2-Methylnapthalene," *Agency for Toxic Substances & Disease Registry*, accessed March 23, 2017, https://www.atsdr.cdc.gov/phs/phs.asp?id=238&tid=43.

[89] Jean P. Dawson, W. W. Thayer, and Jane F. Desforges, "Acute Hemolytic Anemia in the Newborn Infant due to Naphthalene Poisoning: Report of Two Cases with Investigations into the Mechanism of the Disease.," *Blood, J. Hematol.* 13, no. 12 (1958): 1113–25, 1115.

[90] "Illness Associated with Exposure to Naphthalene in Mothballs -- Indiana," Morbidity and Mortality Weekly Report (Centers for Disease Control and Prevention, January 21, 1983), https://www.cdc.gov/mmwr/preview/mmwrhtml/00001236.htm.

[91] Victor Todisco, Jacqueline Lamour, and Laurence Finbero, "Hemolysis from Exposure to Naphthalene Mothballs," *New England Journal of Medicine* 325, no. 23 (December 5, 1991): 1660–61, https://doi.org/10.1056/NEJM199112053252322; H C Lim, "Mothballs: Bringing Safety Issues out from the Closet," *Singapore Medical Journal;* 47, no. 11 (2006): 1003; Daniel L. Sudakin, David L. Stone, and Laura Power, "Naphthalene Mothballs: Emerging and Recurring Issues and Their Relevance to Environmental Health," *Current Topics in Toxicology* 7 (2011): 13–19; Tanveer Singh Kundra et al., "Naphthalene Poisoning Following Ingestion of Mothballs: A Case Report," *Journal of Clinical and Diagnostic Research : JCDR* 9, no. 8 (August 2015): UD01–2, https://doi.org/10.7860/JCDR/2015/15503.6274; Sari Harrar, "The Danger in Mothballs," *Philly.com*, June 14, 2012, http://www.philly.com/philly/blogs/healthy_kids/The-danger-in-mothballs.html.

lifetime cancer risk and the third highest for outdoor exposures.[92] If relied upon for domestic work as well as child care, feminized domestic labor is both exposed to chemicals and responsible for exposure in others.

Looking at the continued use of naphthalene within the Field Museum (as well as other natural history museums) allows for me to see how this value—what should be preserved and to whose benefit—might still subtly operate, especially outside of the context of indigenous materials, as it is used on many biological collections such as pinned insect, mammal skins, etc. So, by drawing attention to the feminized labor of museum, archival, and domestic work, I can situate the politics of naphthalene and the value placed on preservation over the health of laborers. And in domestic spaces as well as in natural history museums, anxieties about change can be prioritized over the health of historically feminized labor. Jessup agonizes that "a single dermestid larva has been observed to damage all pinned insect specimens in a Cornell drawer."[93] Masculinized positions' "dependence on forms of labor, both domestic and otherwise,"[94] such as to conduct scientific research in museums, further highlights how, although curators are occasionally exposed to toxins while preserving specimens during field work, people who work daily in collections, performing archival labor, bear the most exposure due to that the nature of their work is focused on archival tasks within collections—within the Field Museum, many collections workers not only have daily tasks that involve working with the materials that are treated with naphthalene—such as processing loans, curating collections, and databasing or

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[92] Chunrong Jia, Stuart Batterman, and Christopher Godwin, "VOCs in Industrial, Urban and Suburban Neighborhoods, Part 1: Indoor and Outdoor Concentrations, Variation, and Risk Drivers," *Atmospheric Environment* 42, no. 9 (March 1, 2008): 2083–2100, https://doi.org/10.1016/j.atmosenv.2007.11.055.

[93] Wendy Claire Jessup, "Pest Management," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 211.

[94] Sara Ahmed, *Queer Phenomenology: Orientations, Objects, Others* (Duke University Press, 2006), 34.

digitizing materials—but also often have office spaces directly in the collections spaces, exposing them to naphthalene daily. Working with naphthalene and an exposure to its toxicity is a normalized, institutional expectation, as Ahmed describes, "when things become institutional, they recede."[95]

Similarly, the cleanliness of homes and preservation of clothing or linens is foregrounded over the health of those exposed. Ahmed highlights "the ways in which women, as wives and servants [and I would add archivists and museum workers], do the work required to keep such [domestic, archival, and museum] spaces available for men and the work they do."[96] Turning towards the ways in which labor is normalized within domestic spaces, Ahmed contends that "if the objects of phenomenology are domesticated objects—that is, objects one imagines as 'being available' within the familiar space provided by the home—then domesticity of the setting is not allowed to reveal itself."[97] Like within museums, the politics of naphthalene can fall to the background and become a normalized aspect of feminized labor in households. The politics of exposure and health effects in those working with collections are expanded through understanding the multiple ways in which feminized labor is and has been subjected to toxins.

Considering the politics of feminized labor and exposure, I have shown that an expansive lens around materiality allows us to consider a historical connection of natural history to disability, without explicit evidence in the archives. This lens also allows me to think through how disability serves as a pathway to discuss colonial values around materials and spaces—such

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[95] Sara Ahmed, *On Being Included: Racism and Diversity in Institutional Life* (Durham u.a.: Duke University Press Books, 2012), 21.

[96] Sara Ahmed, *Queer Phenomenology: Orientations, Objects, Others*, First Edition edition (Durham: Duke University Press Books, 2006), 31.

[97] Sara Ahmed, *Queer Phenomenology: Orientations, Objects, Others*, First Edition edition (Durham: Duke University Press Books, 2006), 33.

as non-human animal collections as well as domestic spaces—where they may not be readily apparent. To consider the politics of exposure, who is disabled or debilitated through chemical exposure due to the nature of their work, resurfaces how preservation can function for the benefit of some and the detriment of others. In other words, if we think about the people who are exposed to naphthalene, we might be able to draw attention back to—although recent conservation literature and practices have challenged such ideals[98]—how chemical preservation, might in some cases function for the sustaining of the underlying pedagogies, to preserve and maintain a specimen for its *original purpose*. A disability studies lens therefore allows me to think about the subtle politics of exposure, how power subtly operates even when considering non-human collections.

Foregrounding all of those whose experience, values, and labor may be deprioritized, undervalued, or not taken into account, this section has connected multiple spaces in which naphthalene permeates. By showing how museum's colonial values impact multiple spaces and communities, I have drawn an expansive chemical assemblage to first talk about disability within the context of natural history and second, to locate colonial values where they may not be readily apparent. As naphthalene is used not only on Indigenous materials—that may be repatriated—but also insect collections, mammal skins, etc., we can understand a history of colonialism and disability within non-human animals as well. This constellation has allowed for me to talk about a history of disability without explicit evidence of disability in history—through thinking about the ways in which values are embedded within materials, as well as thinking about a material's alternative uses, exposure, and movement.

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[98] Lisa Elkin and Christopher A. Norris, *Preventive Conservation: Collection Storage* (Society for the Preservation of Natural History Collections, 2019).

Conclusion

Through working in archives and museums, as Steedman articulates, one not only breathes life "into the souls who had suffered long ago and who were smothered now in the past," but also breathes in the accumulated dust, debris, and chemicals that have intentionally or unintentionally accumulated.[99] Understanding archives as assemblages—of people, places, policies, attitudes, environments, and materials across time—we can draw in the multiple and expansive histories and entities that co-construct museums and the archival material that represent them. Thus by locating not only the ways in which natural history museums can perpetuate obvious harms as well as address them, as shown by Indigenous communities, and also more subtly perpetuate colonial values, by using chemicals within non-human animal specimens, this research has connected a constellation of experiences through one chemical and its analogues.

This chapter, building off of the previous chapters, has traced the subtleties of disability in history through an attention to materiality. Museums and archives uphold power in many ways. Connecting archives and museums to disability studies uncovers not only the obvious ways in which archives have historically oppressed marginalized people, but also the more concealed ways that it has done so. Although natural history museums may have changing relations to Indigenous communities and gendered labor, through an expansive attention to materiality, it becomes clear that museums may still perpetuate certain politics, practices and perspectives. Through this approach I have challenged the act of preservation, the continued

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[99] Carolyn Steedman, *Dust: The Archive and Cultural History* (New Brunswick, N.J: Rutgers University Press, 2002)., p. 27

institutional epistemologies, and notions of value that can, as Ahmed puts it, "recede"[100] into the background in natural history museums.

Through this lens, efforts against deterioration are framed as not only physically preserving materials and specimens, at the expense of those working in collections and those receiving repatriated materials, but it is also part of the preservation of institutional ideals. An assemblage approach connects the history and uses of naphthalene to how it has been institutionalized over time. Preservation is an anticipatory move against change and for the maintenance of the (mostly white, male) curator or scientist's purpose, for, it's been argued, "even subtle changes may alter the value of the collection for research or other uses."[101] Again "value" is defined for and around the scientific community, so preserving material works explicitly towards the goals of the museum. Chemical preservation becomes the embodied act of continued control in anticipation of change, where the exposure of those working in collections to toxic chemicals has historically been worth the preservation of the "value" of collections.

As part of building towards to crip provenance—a framework of resisting rehabilitative orientations to archival material, and instead of considering all of the people, systems, materials, and spaces that connect disability to history—I've shown how an attention to materiality illuminates histories of disability, colonialism, and values. If we are to think expansively about the subtlety of disability in records and even the absence of records on disability, broadening the assemblage of what can give context to a record is also necessary. A crip provenance therefore

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[100] Sara Ahmed, *On Being Included: Racism and Diversity in Institutional Life* (Durham u.a.: Duke University Press Books, 2012), 21.

[101] Carolyn L. Rose and Catharine A. Hawks, "A Preventive Conservation Approach to the Storage of Collections," in *Storage of Natural History Collections: A Preventive Conservation Approach*, 1St Edition edition (Washington, D.C: Society for the Preservation, 1995), 2.

places focus not only on records, their histories, and context(s) together, but also on what is not in a record—other historical contexts, material uses, and archival practices.

With a focus on the feminized positions which are exposed to naphthalene, I have illustrated just a few of the ways in which systems build on one another as well as how a tracing of the materials used in archives and museums can be further politicized by looking at alternative uses, effects, affects, and power imbalances. The labor of collections workers, through an assemblage approach, is politicized through its disproportionate exposure to toxic chemicals, connection to other feminized labor and historical ties to colonial agendas of control. Likewise, domestic labor has also been historically impacted through the exposure to this carcinogenic substance. A connection to the complexity of the use of naphthalene brings to the forefront problematized notions of value—whose labor and potential detriment is at the expense of masculinized, colonial values. My aim for this project is not to demarcate all preservation within archives and museums as de facto harmful or not productive. There are instances where the preservation of archival material has functioned for liberatory or beneficial purposes.[102] And moreover, there are methods of preservation and pest control, such as freezing, that do not involve chemicals. However, by drawing attention to the politics of preservation, I aim to unsettle them as de facto 'good'. While the critiques of this chapter have primarily focused on naphthalene, I hope this framework spurs questions for other chemical uses in museums and archives as well, to draw how complex histories, problematize accepted practices, and further uncover values in memory institutions with a disability studies lens.

[102] For example, Michelle Caswell, et. al. has shown the ontological, epistemological, and social impacts representation in community archives. Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (June 1, 2016): 56–81, doi:10.17723/0360-9081.79.1.56.

Moreover, this lens has allowed me to talk about disability within the context of the Field Museum without much explicit evidence. By understanding how systems of value become embodied in preservation practices as well as how those practices permeate multiple instances of feminized labor, I can consider the history of naphthalene as one about disability. While disabled people might not always have explicit forms of documentation, especially in histories outside of medical, asylum, and specialized narratives, this framework provides a lens to consider the politics of materiality as connected to disabled people throughout time. Naphthalene's use grew within the late nineteenth century, initiating toxic exposure, illness, disability, and debility. Drawing attention to these histories as well as how they are bound up in assemblages of display, knowledge production, organization, and labor allows for me to center the proximal ways in which disabled people are subtly present in history.

Although today naphthalene is used less in mothballs (replaced by p-dichlorobenzene [PDB], as a less flammable toxin, but arguably just as toxic[103]), it "remains readily available, e.g., sold as 'old fashioned mothballs' or flakes,"[104] and is still a source for the millions of tonnes of phthalic anhydride produced a year, which is employed in the making of plastics and plasticizers.[105] Considering how the chemical is not only used, but also deeply rooted within

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[103] Richard M. Hession et al., "Multiple Sclerosis Disease Progression and Paradichlorobenzene: A Tale of Mothballs and Toilet Cleaner," *JAMA Neurology* 71, no. 2 (February 1, 2014): 228–32, https://doi.org/10.1001/jamaneurol.2013.4395.

[104] Chunrong Jia and Stuart Batterman, "A Critical Review of Naphthalene Sources and Exposures Relevant to Indoor and Outdoor Air," *International Journal of Environmental Research and Public Health* 7, no. 7 (July 2010): 2903–39, https://doi.org/10.3390/ijerph7072903.

[105] R. Deeb, A. Ghanbari, and B. L. Karihaloo, "Development of Self-Compacting High and Ultra High Performance Concretes with and without Steel Fibres," *Cement and Concrete Composites* 34, no. 2 (February 1, 2012): 185–90, https://doi.org/10.1016/j.cemconcomp.2011.11.001; Mami Ohno, Toshikazu Takata, and Takeshi Endo, "Synthesis of a Novel Naphthalene-Based Poly(Arylene Ether-Ketone) by Polycondensation of 1,5-Bis(4-Fluorobenzoyl)-2,6-Dimethylnaphthalene with Bisphenol A," *Journal of Polymer Science Part A: Polymer Chemistry* 33, no. 15 (November 15, 1995): 2647–55, https://doi.org/10.1002/pola.1995.080331511; N Kiran, E Ekinci, and C. E Snape, "Recycling of Plastic Wastes via Pyrolysis," *Resources, Conservation and Recycling* 29, no. 4 (June 1, 2000): 273–83, https://doi.org/10.1016/S0921-3449(00)00052-5.

global industries that benefit from the sale of a chemical that is harmful to people and the environment,[106] —not to mention how naphthalene and its production negatively impact the environment, which is in direct contradiction to narratives of ecological conservation within many natural history museums—naphthalene's assemblage could be further expanded to additional facets of power and politics.

The goal for this chapter is to surface and therefore complicate preservation via a queer phenomenological approach to assemblages, and provide a platform for understanding how power operates in complex ways, at a time where we, as archivists and museum workers, want to understand the ways in which we may be complicit in systems of oppression. This is just one avenue to understand how Native communities, Disabled people, and feminized laborers are harmed by legacy systems, and could easily be expanded to analyze how archivists are notoriously overworked and underpaid, and understaffed, experience harm through performing repetitive labor, witness traumatic materials, or handle other toxic materials. In anticipation of confronting the ways in which colonial power operates in a wide array in institutions, we need to first assess the ways in which it operates that may not be immediately evident as well as how we inadvertently maintain a colonial and disabling project.

I have demonstrated how a crip provenance can extend broadly to identify ways of talking about disability in history as well as how legacies of ableism and colonialism are historically interwoven. This chapter sets the stage for the next: by considering the values and impacts of materiality, we can expand to considering how the materiality of spaces shapes

[106] Chunrong Jia and Stuart Batterman states that "Based on industry reports, the U.S. moth preventative consumer sales totals $14 million annually, of which 41% can be identified as naphthalene products." And "A Canadian material emission database listed naphthalene in 41 of 69 commonly used materials." Chunrong Jia and Stuart Batterman, "A Critical Review of Naphthalene Sources and Exposures Relevant to Indoor and Outdoor Air," *International Journal of Environmental Research and Public Health* 7, no. 7 (July 2010): 2903–39, https://doi.org/10.3390/ijerph7072903.

experiences. Thus, Chapter Six takes up the final facet of crip provenance—spaces—to show the ways in which values can be embodied within archival spaces which drastically shape disabled people's experiences of them.

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Chapter Six: Spaces
"it wasn't necessarily designed with that experience in mind": The Affect of Archival (In)Accessibility & "Emotionally Expensive" Spatial (Un)Belonging

Introduction

When the Hunters Point Library opened in Queens, New York in September 2019, architects, librarians, museum workers, and archivists alike revered its innovative and modern design. The library's pinnacle architectural feature—cascading tiers of aisles, lined with a staircase that's mirrored with a carved-out window—was celebrated as architecturally innovative, making the building "among the finest and most uplifting public buildings New York has produced so far this century."[1] Yet, while the $41 million project was praised as reinventing public library architecture through beautiful design, disabled people and disability advocates highlighted a huge oversight: the central maze-like structure contained only one elevator, which did not access all floors.

The Hunters Point Library is just one of many, many public information gathering spaces—new and old—that are inaccessible to people with disabilities (as well as older, injured, and sick people), many of which include not only libraries but also museums and archives. Although awareness around accessibility has increased in the past 30 years—such as museums developing multisensory tours[2] and the American Library Association developing accessibility

[1] Michael Kimmelman, "Why Can't New York City Build More Gems Like This Queens Library?," *The New York Times*, September 18, 2019, sec. Arts, https://www.nytimes.com/2019/09/18/arts/design/hunters-point-community-library.html.

[2] For examples see: Crystal Bridges Museum of American Art, "Multisensory Tours at the Museum," accessed March 31, 2020, https://crystalbridges.org/blog/multisensory-tours-at-the-museum/; Wendy L. Dodek, "Bringing Art to Life through Multi-Sensory Tours," *Journal of Museum Education* 37, no. 1 (March 1, 2012): 115–24, https://doi.org/10.1080/10598650.2012.11510723; Queen Museum, "Multi-Sensory Tour Kit," accessed March 31, 2020, https://queensmuseum.org/2010/06/multi-sensory-tour-kit; The Design Museum, "Multisensory Tours," Design Museum, accessed March 31, 2020, https://designmuseum.org/plan-your-visit/access/multisensory-tours;

toolkits for disabled patrons[3]—archives, special collections, and libraries can still have inaccessible spaces, materials, and therefore uses. Reasoning for inaccessibility varies: older buildings and historical landmarks can't always be retrofitted with new materials; many organizations cite how architectural adjustments are expensive; and funds can also be lacking for digitization, image descriptions, and accessible technology; to name a few. This chapter asks what does that inaccessibility tell disabled people about how disabled communities are—or rather are not—valued by academic institutions, spaces where we historically have been excluded?

In the previous chapters, I have shown how an attention to *people* can show how archival materials can produce a sense of community, even in their absence; how drawing attention to *language and systems* can facilitate complicating and contextualizing records on disability; how the politics of *materiality* can illuminate complicated and interconnected histories around disability and ableism; and how each of these *not only adds context to records but also allows for the centering of disability within archival narratives*. As the final facet of crip provenance—which considers all of the relationships that are created because materials on disability are duplicated and dispersed which adds to a records' context—this chapter demonstrates disabled people's relationships to space and place as well as how archival spaces, accessibility, and archival experiences all add context to records and therefore should be considered as part of provenance. Like Chapter Three, this chapter builds towards a crip provenance by highlighting the contemporary ways in which archival materials are experienced and how the spaces in which

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Ezgi Ucar, "Multisensory Met: Touch, Smell, and Hear Art," The Metropolitan Museum of Art, accessed March 31, 2020, https://www.metmuseum.org/blogs/digital-underground/2015/multisensory-met.

[3] The Association of Specialized Government and Cooperative Library Agencies. "Library Accessibility Toolkits: What You Need to Know." Accessed March 31, 2020. https://www.asgcladirect.org/resources/.

they are kept are also political, which further adds context to records. Disability studies scholar Tanya Titchkosky, in *The Question of Access Disability, Space, Meaning*, states "'access' *is* a way of bringing life to consciousness, a form of oriented social action, and a way of relating to people and places."[4] In other words, physical spaces embody and reflect social relations through which one can feel understood, included or a sense of belonging and accessibility is multivalent. As the final facet of the constellation that I've laid out in this dissertation—people, systems, materials, and space—this chapter shows how interwoven the previous four are with spaces and accessibility. This chapter asks: how do disabled researchers experience accessibility and/or inaccessibility in physical and digital archival spaces? And what affects, emotions and feelings around in/accessibility impact disabled researchers' archival experiences? Placing focus on accessibility as part of the context of records—which shapes how the content of records is experienced—expands a crip provenance to consider the multiple and interconnected ways in which archives can produce a sense of symbolic annihilation.

Returning to the lived experiences of disabled people, this chapter utilizes interviews with disabled people to train a critical lens on the affects of accessibility. Affects, or "those visceral forces beneath, alongside," internal, conscious, semi-conscious, or unconscious emotions,[5] are felt through spatial interactions, especially as disabled people navigate the prevalence of inaccessibility. I originally sought to investigate the impacts of the representation of disability in archives, but my subjects told an additional story, that of archival accessibility. The theme of accessibility arose organically in all ten interviews and formed three distinct findings around their affective responses to archival spaces.

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[4] Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning* (University of Toronto Press, 2011), 3.

[5] Seigworth, Gregory J. and Melissa Gregg. *The Affect Theory Reader*. Duke University Press, 2010, 1.

In this chapter, I will first give an overview of the multiple ways accessibility is understood and experienced. With a history in disability activism, the Americans with Disability of Act of 1990 has influenced the increase of accessibility in public spaces. Also addressing accessibility, design principles, such as Universal Design, emerged as ways to produce spaces with disabled bodyminds at the fore. As Aimi Hamraie writes, "the built world is inseparable from social attitudes, discriminatory systems, and knowledge," therefore accessibility has also been investigated as a cultural and social way of producing affective responses of belonging and exclusion for disabled people.[6] With this literature in mind, I will describe three key findings from the interview data. First, participants highlighted how many disabled people do not have access to archives or other academic institutions. This foregrounded the awareness that participants had around their privileges in being able to do archival work and produced some anxiety around being grateful for their privileges. Second, disabled archival users described how they experience barriers to accessibility not only at a fundamental level—of physically being able to get into a building or archives room—but also through archives' policies and the ways in which archival work is expected to be done. These experiences of navigating inaccessibility show the overwhelming prevalence in the ways that archival spaces can be inaccessible to disabled patrons and content creators, which sets the stage for the final finding. The varying levels of inaccessibility—the ways in which accessibility is implemented and materials are treated—greatly impact how disabled researchers feel disabled people are valued and feel a sense of belonging in archival spaces. I illustrate different affects, such as a sense of the devaluation of accessibility and disability as an organizing category, being "part of the trash," deprioritized, and erased. Through these affects, I utilize interviewee Therí Pickens' words to develop the term

[6] Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (University of Minnesota Press, 2017), 3, 14, emphasis theirs.

"emotionally expensive" to emphasize how the prevalence of archival inaccessibility comes at a great cost to disabled archival users, not only producing a sense of unbelonging but also often preventing them from using and/or donating to archives. These unintended findings, emerging out of the data, demonstrate how central accessibility is to disabled people's lives—it is almost impossible to talk about our experiences of spaces, materials, and technologies without discussing how we navigate the multiple barriers to access them.

Accessibility, Legislation & Design

Accessibility has been constructed through various lineages and is currently multiply understood. From simply 'good' design, to design specifically by and for disabled people, access has been constructed, as I will explain (1) through activism—through identifying the ways in which spaces shape disabled people's lives—(2) through legislation—such as the Americans with Disabilities Act that defines how spaces should be designed to increase access to public places—and (3) through design principles—such as Universal Design that emphasizes flexible and equitable uses for varying bodyminds. I will cover these aspects of the ways in which accessibility is defined and understood, as well as how libraries, archives and museum spaces have addressed it. In investigating how access and archival spaces are experienced, my intent here is to outline the ways in which accessibility is understood as well as the affective impacts of both accessibility and archives.

As discussed throughout this dissertation, the social model of disability is often cited as a central concept within the fight for disability rights as it addresses the social constructs that inhibit disabled people from having equal access to opportunities and resources that would otherwise help them to "participate fully in society, to live independently, to undertake

productive work and to have full control over their own lives."[7] As Kim Nielsen notes, "Groups of disabled veterans, parents, blind people, deaf people, and other physically disabled persons had sought to shape their own lives in the decades leading up to the disability rights movement," arguing that disability is not simply a medical issue, but a socially shaped condition of discrimination.[8] Rooted in disability activism and highlighting the social construction of disability, the social model shifts attention from the disabled bodymind and onto inaccessible environments and discriminatory attitudes that impact disabled people's lives. Tom Shakespeare highlights how it "has been effective politically in building the social movement of disabled people. It is easily explained and understood, and it generates a clear agenda for social change."[9] Therefore the social model is often credited with being a foundational concept in the disability rights movement and the passing of the Americans with Disabilities Act (ADA) in 1990.[10]

Arguably the most well-known US federal legislation for disabled people, the Americans with Disabilities Act (ADA) of 1990 built on previous legislation such as: the 1977 demonstrations at The United States Department of Health, Education, and Welfare (HEW) offices (otherwise known as the Section 504 sit-ins); the Architectural Barriers Act of 1968; the Rehabilitation Act of 1973; The Individuals with Disabilities Education Act (IDEA) of 1975; and The Fair Housing Amendments Act of 1989.[11] The ADA was informed by centuries of activism

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[7] Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard Davis, 2 edition (New York: Routledge, 2006), 200.

[8] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 162.

[9] Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis (Routledge, 2016), 195–203, 198.

[10] 108th Congress, "Americans With Disabilities Act of 1990," Pub. L. No. Public Law 101-336 (1990).

[11] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013),Colker, Ruth. *The Disability Pendulum: The First Decade of the Americans With Disabilities Act*. NYU Press, 2005.

and protests against the discrimination, harassment and injustices that disabled people face in everyday life. Activism such as that of Robert Payne and disabled miners in the 1960s,[12] the independent living movement in the 1970s, many accounts of disability activists intervening to make spaces accessible, "smashing sidewalks with sledgehammers and pouring new curb cuts with bags of cement or asphalt,"[13] and disabled maker spaces preceded and shaped the ADA. Today, the ADA is one of the most prominent pieces of legislation in North America that incentivizes public spaces being accessible. From government buildings, educational settings (including housing), hotels, and public transportation, the ADA requires that public spaces have "a path of travel safe harbor" to access the facilities of public entities. Such means of architectural access include accommodations such as wheelchair ramps, elevators, lifts, railings, braille signage, and visible alarm systems, which make public spaces more accessible to disabled and d/Deaf communities.[14] Lawyer and law scholar Ruth Colker remarks how, because of the ADA, "Cities have installed thousands of curb ramps, buses have routinely become equipped with lifts, and hotels often provide accessible rooms for their guests." She emphasizes that, "Although many of these changes may have been required by state law that preceded enactment of the ADA, it took national attention to a new civil rights statute to provide the impetus for these important changes."[15] The ADA also extended anti-discrimination protection to individuals with "mental impairments" in attempts to provide more opportunities for employment, education and housing to disabled people who faced discrimination outside of physical barriers. The ADA

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[12] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 160.

[13] Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (University of Minnesota Press, 2017), 95.

[14] 108th Congress, "Americans With Disabilities Act of 1990," Pub. L. No. Public Law 101-336 (1990).

[15] Colker, Ruth. *The Disability Pendulum: The First Decade of the Americans With Disabilities Act*. NYU Press, 2005.

and the activism that propelled it has resulted in more opportunities for education, employment, housing, public transportation, and participation in everyday activities for disabled people in the U.S.

While these nondiscrimination standards for disabled people have increased accessibility, the ADA faces criticism in its application. Colker observes how “The Supreme Court has interpreted the ADA narrowly, often disappointing the disability rights community,” as it interprets the term 'individual with disability' narrowly.[16] Historian Kim E. Nielsen notes that “The reality of the ADA, [is that]... it has been consistently tested and eroded in courts, and sometimes ignored in practice.”[17] Sociologist Teresa L. Scheid, examining employer’s attitudes around hiring people with mental disabilities, highlights how even though employers were aware of their biases, they were also likely to hold stigmatized attitudes.[18] And Suzanne Wilhelm points out that despite the ADA, “Students with cognitive impairments may not be entitled to ADA protections,” especially if they lack documentation or if it's decided that there is “no reasonable way to accommodate their functional limitation without lowering academic standards.”[19] As a rights-based efforts to effect architectural, education, citizenship and self determination human rights, Nielsen highlights, “The movement focused on legal efforts to prohibit discrimination in employment and education, access to public spaces and public transportation, and on institutional

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[16] Ruth Colker, *The Disability Pendulum: The First Decade of the Americans With Disabilities Act* (NYU Press, 2005), 7.

[17] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 181.

[18] Teresa L. Scheid, “Stigma as a Barrier to Employment: Mental Disability and the Americans with Disabilities Act,” International Journal of Law and Psychiatry 28, no. 6 (November 1, 2005): 670–90, https://doi.org/10.1016/j.ijlp.2005.04.003.

[19] Suzanne Wilhelm, “Accommodating Mental Disabilities in Higher Education: A Practical Guide to ADA Requirements,” *Journal of Law & Education* 32, no. 2 (2003): 217–38, 236.

transformations that better enabled the self-determination of those with disabilities."[20] Although the ADA has transformed some public spaces and systems, as Sarah Parker Harris et. al. remark:

> In spite of these advances, there are also arguments that the ADA has fallen short of its implementation goals because the population of people with disabilities continues to be excluded from much of mainstream society and is less likely to have access to various social events, paid labor, healthcare, and education. More telling perhaps is the opinions of people with disabilities themselves. A recent survey of individuals with disabilities conducted by the National Organization on Disability found that a majority (61%) of people surveyed indicates that the ADA had made no difference in their lives.[21]

These arguments indicate that many public spaces, restaurants, bathrooms, educational settings, public transit stations, and buildings—to name a few—remain inaccessible for disabled people today. And furthermore, they highlight that discrimination and inaccessibility extends well beyond public spaces and physcial accessibility—while the ADA has transformed some public spaces to be more accessible, the limited scope of this rights-based framework still leaves disabled people facing inaccessibility and discrimination.

Also during the 20th century, a flexible, inclusive design philosophy centered around accessibility for both disabled and nondisabled users was unfolding: Universal Design. Centered around design for more equitable and flexible use of spaces and objects, the Principles of Universal Design provided aesthetic ways to foreground disability within design. This concept of

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[20] Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2013), 161.

[21] Sarah Parker Harris et al., "Scoping Review of the Americans with Disabilities Act: What Research Exists, and Where Do We Go from Here?," *Disability Studies Quarterly* 34, no. 3 (June 4, 2014), https://doi.org/10.18061/dsq.v34i3.3883.

accessibility was less of a strategy to get from point A to point B, and more a way to think creatively about how spaces are used and designed. Spaces such as the Ed Roberts Campus in Berkeley, CA were designed using the Principles of Universal Design to emphasize usability for disabled people while also creating an aesthetic experience: the building not only features elevators with large buttons, braille placards, wide corridors, automatic doors, accessible restrooms, and a fragrance–free workplace policy but also centers a bright red helical ramp that winds upward through the center of the building—a central design feature which is usable by many different types of bodyminds and foregrounds the many ways in which disabled people interact with spaces. Given its history in disability activism, the Principles of Universal Design can be applied as they were originally intended when coined by Ronald Mace in 1985: to anticipate flexible and equitable access for the most marginalized. They have been applied to learning environments and educational pedagogies to not only accommodate students with physical disabilities, but also increase access to education for people with intellectual, cognitive, and mental disabilities.[22] However, the principles have also been interpreted as simply 'good' design, spurring concepts like ergonomics, which sometimes focus less attention on the needs of disabled people and focus more on efficiency and productivity.[23]

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[22] For example, see: Fred Spooner et al., "Effects of Training in Universal Design for Learning on Lesson Plan Development," *Remedial and Special Education* 28, no. 2 (March 1, 2007): 108–16, https://doi.org/10.1177/07419325070280020101; Peggy Coyne et al., "Literacy by Design: A Universal Design for Learning Approach for Students With Significant Intellectual Disabilities," *Remedial and Special Education* 33, no. 3 (May 1, 2012): 162–72, https://doi.org/10.1177/0741932510381651; Kavita Rao, Patricia Edelen-Smith, and Cat-Uyen Wailehua, "Universal Design for Online Courses: Applying Principles to Pedagogy," Open Learning: The Journal of Open, Distance and e-Learning 30, no. 1 (January 2, 2015): 35–52, https://doi.org/10.1080/02680513.2014.991300.

[23] Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (University of Minnesota Press, 2017).

Accessibility & Libraries, Archives & Museums

Within libraries, archives, and museums (LAMs), accessibility has been addressed as a way to include more disabled patrons, often relying on the ADA as a guideline. Due to their public-facing aspects, many libraries and museums have developed accessible entrances, tactile exhibits, and other disability policies to include more disabled visitors. The ADA as well as other accessibility guidelines (such as Web Content Accessibility Guidelines) have laid the foundation for basic changes in accessibility to LAMs and the materials they hold. Libraries, for one, are often known for developing ways to accommodate disabled patrons.[24] Librarians Michelle Kowalsky and John Woodruff, for example, have recently created a resource that covers many ways in which libraries can not only comply with ADA standards, but also create inclusive spaces for people with disabilities. They provide many strategies to both involve people with disabilities in planning, employment, and collaboration as well as to make spaces and materials accessible to disabled patrons, such as installing slip resistant flooring and providing alternatives to printed text.[25] Others have addressed how libraries can better serve disabled library patrons, support disabled librarians, and increase accessibility compliance while creatively supporting disabled people.[26] Disabled librarian, J. J. Pionke states that "While the law is clear that

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[24] Theresa S. Arndt and Anna Schnitzer, "Guest Editorial: Library Services for People with Disabilities," *Reference Services Review* 46, no. 3 (January 1, 2018): 321–24, https://doi.org/10.1108/RSR-08-2018-089.

[25] Michelle Kowalsky;John Woodruff, *Creating Inclusive Library Environments: A Planning Guide for Serving Patrons with Disabilities* (Amer Library Assn Editions, 1796).

[26] For example see the special issue of Library Trends on "Disabled Adults in Libraries": Jessica Schomberg and Shanna Hollich, "Introduction," Library Trends 67, no. 3 (May 8, 2019): 415–22, https://doi.org/10.1353/lib.2019.0003. Other examples include: Nahid Bayat Bodaghi, Loh Sau Cheong, and A.n. Zainab, "Librarians Empathy: Visually Impaired Students' Experiences Towards Inclusion and Sense of Belonging in an Academic Library," *Journal of Academic Librarianship* 42, no. 1 (January 2016): 87–96, https://doi.org/10.1016/j.acalib.2015.11.003; Joanne Kaeding, Diane L. Velasquez, and Deborah Price, "Public Libraries and Access for Children with Disabilities and Their Families: A Proposed Inclusive Library Model," *Journal of the Australian Library & Information Association* 66, no. 2 (June 2017): 96–115, https://doi.org/10.1080/24750158.2017.1298399; Alistair McNaught, "Accessible Libraries - Strategic Practice," *ALISS Quarterly* 10, no. 1 (October 2014): 30–32; Joanne Oud, "Systemic Workplace Barriers for Academic

accommodations must be offered to people who ask for them, the law does not stipulate that employers have to understand, educate, or embrace the person with a disability, and that is the crux of the issue."[27] Pionke advocates not just for ADA compliance but proposes developing a culture of equity, using Universal Design, which includes educating all employees about disability and implicit bias, as well as modeling appropriate behaviors around equity and equality.[28]

Museums also have begun not only to take into consideration accessibility standards of the ADA but also the multiple ways in which people experience exhibits.[29] For example, the Field Museum advertises wheelchair accessible bathrooms and entrances as well as captioned videos, and the Smithsonian Institution and American Museum of Natural History explicitly offer exhibit transcripts, tactile exhibits, and American Sign Language interpreters.[30] The Field Museum and the American Museum of Natural History also provide special tours and hours for

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Librarians with Disabilities | Oud | College & Research Libraries," accessed May 28, 2020, https://doi.org/10.5860/crl.80.2.169; Charlie Remy, Priscilla Seaman, and Kelly Myer Polacek, "Evolving from Disability to Diversity," *Reference & User Services Quarterly* 54, no. 1 (Fall 2014): 24–28; Jessica Schomberg, "Disability at Work: Libraries, Built to Exclude," *Politics and Theory of Critical Librarianship*, February 1, 2018, 111–23; Kyunghye Yoon, Laura Hulscher, and Rachel Dols, "Accessibility and Diversity in Library and Information Science: Inclusive Information Architecture for Library Websites," *The Library Quarterly* 86, no. 2 (April 1, 2016): 213–29, https://doi.org/10.1086/685399; "Accessibility for Justice: Accessibility as a Tool for Promoting Justice in Librarianship – In the Library with the Lead Pipe," accessed May 28, 2020, /2017/accessibility-for-justice/.

[27] J. J. Pionke, "The Impact of Disbelief: On Being a Library Employee with a Disability," *Library Trends* 67, no. 3 (May 8, 2019): 423–35, https://doi.org/10.1353/lib.2019.0004.

[28] J. J. Pionke, "The Impact of Disbelief: On Being a Library Employee with a Disability," *Library Trends* 67, no. 3 (May 8, 2019): 423–35, https://doi.org/10.1353/lib.2019.0004.

[29] For a special issue specifically on museums and blindness, see: Nina Levent, Georgina Kleege, and Joan Muyskens Pursley, eds., "Double Issue: Museum Experience and Blindness; General Issue," *Disability Studies Quarterly* 33, no. 3, accessed March 9, 2020, https://dsq-sds.org/issue/view/104.

[30] "Accessibility," Text, *The Field Museum*, (November 23, 2016), https://www.fieldmuseum.org/visit/accessibility. "Accessibility," *AMNH*, accessed March 1, 2017, http://www.amnh.org/plan-your-visit/accessibility. "Accessibility Information: Plan Your Visit: Smithsonian National Museum of Natural History," accessed March 1, 2017, https://naturalhistory.si.edu/visit/accessibility.htm.

visitors with sensory processing needs.[31] Some museums have taken it further, implementing sensory experiences, including neurodiverse visitors,[32] as well as blind/low vision visitors.[33] While the ADA has functioned to improve the accessibility of libraries and museums, it also has functioned as a starting point to also think through the multiple ways in which disabled patrons navigate exhibits, locate information, and experience an institution.

Scholars and activists have identified the gap of implementation of accessibility standards specifically in archival spaces. While libraries, for one, are often known, "both complying with and shaping legal requirements that relate to library services and access to information,"[34] archives have been criticized both for lacking in their compliance with the ADA as well as in failing to innovate experiences for disabled users. Angela Gallagher critiques, "While the discipline of history, like much of the rest of society, has gradually become more accommodating of some visible physical disabilities in the last decades, the accommodation of intellectual and invisible disabilities has lagged."[35] She continues, stating that:

> Today, ADA compliance within archives primarily extends to individuals with visible physical disabilities, although this too can be uneven. Standard accommodations include wheelchair ramps and accessible entrances, bathrooms, and seating. Some archives, such

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[31] "Accessibility," Text, *The Field Museum*, (November 23, 2016), https://www.fieldmuseum.org/visit/accessibility. "Accessibility," *AMNH*, accessed March 1, 2017, http://www.amnh.org/plan-your-visit/accessibility.

[32] Elizabeth Merritt, "Neurodiversifying the Museum," *American Alliance of Museums* (blog), January 10, 2017, https://www.aam-us.org/2017/01/10/neurodiversifying-the-museum/.

[33] Nina Levent, Georgina Kleege, and Joan Muyskens Pursley, "Museum Experience and Blindness," *Disability Studies Quarterly* 33, no. 3 (May 12, 2013), https://doi.org/10.18061/dsq.v33i3.3751.

[34] Theresa S. Arndt and Anna Schnitzer, "Guest Editorial: Library Services for People with Disabilities," *Reference Services Review* 46, no. 3 (January 1, 2018): 321–24, https://doi.org/10.1108/RSR-08-2018-089.

[35] Angela Gallagher, "Archives and the Road to Accessibility | Perspectives on History | AHA," July 15, 2019, https://www.historians.org/publications-and-directories/perspectives-on-history/summer-2019/archives-and-the-road-to-accessibility.

> as those run by the National Archives and Records Administration, offer some materials in braille or other formats accessible to people with visual disabilities, but many do not. Researchers who are deaf or hard of hearing may encounter communication obstacles in smaller archives that lack interpretive staff.[36]

Online and analog archival collections vary greatly in accessibility—from archival spaces being located in physically inaccessible buildings, to digital records not being described for blind or low vision users. For example, all U.S. National Archives and Records Administration (NARA) buildings are ADA compliant and NARA has five copies of the Constitution and Declaration of Independence in braille. Their accessibility policy offers options for patrons to request ASL interpreters, CART services, wheelchairs, and request other "reasonable accommodations" in order "to provide individuals with disabilities equal access to electronic information and data comparable to those who do not have disabilities unless an undue burden would be imposed on the agency."[37] Such interpretable policies might leave potential visitors with questions about what types of accomodations, other than the ones listed, are possible and "reasonable". The Society of American Archivists (SAA) hosts multiple accessibility resources online, but it is unclear which archives implement them and to what degree. And other archives, such as Lesbian Herstory Archives in New York, remain ADA non-compliant, and/or, lack accessibility information all together. Whether due to lack of knowledge, compliance, or funds, archives have varying levels of accessibility for disabled users and contributors.

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[36] Angela Gallagher, "Archives and the Road to Accessibility | Perspectives on History | AHA," July 15, 2019, https://www.historians.org/publications-and-directories/perspectives-on-history/summer-2019/archives-and-the-road-to-accessibility.

[37] U.S. National Archives and Records Administration, "Accessibility," National Archives, August 15, 2016, https://www.archives.gov/global-pages/accessibility.

The ways in which the ADA has been implemented within museum, library, and archival spaces varies greatly. Each institution, as I have shown, interprets the ADA and specifies what levels of access are provided (i.e. building ramps, bathrooms, braille etc.) and what can be requested (i.e. wheelchairs, interpreters, CART services, etc.), leading to not only varying levels of access, but also inaccessible spaces that do not even comply with the ADA. Highlighting these inconsistencies points out how navigating accessibility policies, figuring out access possibilities, and understanding accessibility outside of physical accommodations might be barriers to access in and of themselves.

Accessibility & Affect

The way in which accessibility is addressed affectively impacts how disabled people feel a sense of belonging within spaces in general. Aimi Hamraie describes how, "the built world is inseparable from social attitudes, discriminatory systems, and knowledge about which users designers must keep in mind," adding how "*making* built environments is an exercise of power entangled with the politics of *knowing*."[38] And Titchkosky remarks that, "In the university, for example, people require access to buildings, washrooms, classrooms, offices, or access to filling out forms; people require access to news, policies, and reading lists, as well as to professors and events; people require access to a sense of the camaraderie, conversation, and connections that accompany academic life. In short, people require access to a general *feeling of legitimate participation, meaningfulness, and belonging.*"[39] Likewise, Elizabeth Ellcessor has complicated how people with disabilities are excluded via "cultural accessibility": how the lived experience

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[38] Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (University of Minnesota Press, 2017), 3, 14, emphasis theirs.

[39] Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning*, 2 edition (Toronto: University of Toronto Press, Scholarly Publishing Division, 2011), 8, emphasis mine.

of access is not flat nor simple and involves complex interactions including emotions and shifting interactions. Access, she proposes, is therefore not a binary, and is grounded in Disability culture.[40] She argues that accessibility is not just about checking a box, "This is the kind of emotional access described by bloggers with disabilities—not an attitude of tolerance or accommodation but an active welcome and recognition of disability as a part of life that brings its own valuable perspectives."[41] Similarly, Mia Mingus states that "Access for the sake of access is not necessarily liberatory, but access for the sake of connection, justice, community, love and liberation is."[42] Accessibility is not just about physical navigation, but is an emotional, affective experience that is tied to feeling a sense of belonging, feeling valued and cared for.

As covered in Chapter Three of this dissertation, archives affectively impact those who use them through the ways in which people are represented, mis-represented, and/or erased in archival material. Many historically marginalized communities feel a sense of, as Caswell, Cifor and Ramirez term, "symbolic annihilation" through the ways they are represented in archives. And Chapter Three demonstrated that disabled archival users feel a similar sense of violence through the ways that disabled people are historically represented. In contrast, community archives—archives built and maintained by the communities that they represent—have been found to have a profound impact on people feeling a sense of belonging. Caswell, Cifor and Ramirez describe this phenomenon as "representational belonging," or "the ways in which community archives give those left out of mainstream repositories the power and authority to

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[40] Elizabeth Ellcessor, *Restricted Access: Media, Disability, and the Politics of Participation* (New York London: NYU Press, 2016), 184.

[41] Elizabeth Ellcessor, *Restricted Access: Media, Disability, and the Politics of Participation* (New York London: NYU Press, 2016), 184, 194.

[42] Mia Mingus, "Access Intimacy, Interdependence and Disability Justice," *Leaving Evidence* (blog), April 12, 2017, https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/.

establish and enact their presence in archives in complex, meaningful, and substantive ways."[43] They stated that:

> Although any records—regardless of the type of institution stewarding them—have the potential to produce affective impact, we posit that community archives have been at the forefront of documenting and responding to communities, and producing both affirmations of existence and feelings of belonging among the community, members they serve.[44]

In addition to representation, archival spaces and policies affectively impact users. Jarette Drake, for one, highlights how archival reading rooms can be spaces of surveillance while also having strict guidelines for how patrons should behave: "How oppressive it is of archivists to expect users to consult documentary records that chronicle the peaks and valleys of humanity — love, hate, war, abuse, joy, humor — and display no auditory or affective response."[45] While Drake's critique highlights the inherent whiteness and normative ways in which one is expected to act in archival spaces, this example also emphasizes how such guidelines are also a form of ableism, where they enforce sanist and audist norms of behavior. Archival representation, spaces, and uses can all impact users' affective experiences of archives and can produce barriers to navigating archival material.

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[43] Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (June 1, 2016): 56–81, https://doi.org/10.17723/0360-9081.79.1.56, 57.

[44] Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (June 1, 2016): 56–81, https://doi.org/10.17723/0360-9081.79.1.56, 76.

[45] Jarrett M. Drake, "Liberatory Archives: Towards Belonging and Believing (Part 1)," October 22, 2016, https://medium.com/on-archivy/liberatory-archives-towards-belonging-and-believing-part-1-d26aaeb0edd1.

Given the uneven and unequal ways in which archival spaces have implemented accessibility *and* the ways in which archival spaces and in/accessibility are experienced affectively, this chapter investigates a crucial area around how accessibility impacts one's experience in archival spaces. This chapter investigates the affects, emotions and feelings around how disabled researchers experience accessibility and/or inaccessibility in physical and digital archives. Filling a gap in the literature, which has yet to focus much attention on how disabled archival users are affectively impacted by accessibility, this chapter will bring to light how archival decisions and design shape how disabled people navigate, use, are prevented from using, or even avoid archives.

Findings

Finding 1: Awareness of the Privileges of Access

Notably, before discussing their own issues around accessing archives, interviewees often first remarked on the ways in which other disabled people could be excluded from accessing archives—many noted the privileges they held in being able to access materials in the first place. Disabled postdoctoral researcher, Stefan Sunandan Honisch noted his sensory privilege, which the blind and d/Deaf subjects of the records—or those who share those disabilities—wouldn't be able to access:

> I'm still able to gain access to these materials in ways that blind and deaf researchers for example, might not. So then the questions about accessibility and representation become even more complicated because it's not then simply about how are people represented in the archives, but researchers perhaps then also participating in a certain kind of sensory

> economy or are a certain kind of circulation and sustenance of these archival records that perpetuate and sort of circumscribe the question of access.[46]

In other words, researchers activate records through acts of access. Disabled scholar and poet, Travis Chi Wing Lau identified a similar privilege:

> I have to fully admit the fact that… I'm privileged enough not to have to require a lot of accommodations, but I know for my colleagues who do, it is an ordeal each and every time; if they need say, a special piece of accessible technology or they need to bring an inhaler medication, I know they get all sorts of sort of crap by people who are working in front. 'You can't bring that into the archive' or like, 'that's going to be a problem.' I can see why some people would just be like, 'I just don't wanna do this at all. I'll wait for the digitized versions. I can access it far more comfortably.'[47]

Blind historian, Alida Boorn described using archival material and bringing an assistant with her to read written materials out loud: "I'd say I've always just been very, very lucky. I don't know the other people you've spoken with, but there was never any problem with having someone read to me."[48] She continued, "I think it helped a little bit too because when I was at Wichita State, I did take a few archival management classes and museum management course classes, and I think they were graduate level. And I think maybe that helped too because I already knew the rules. I knew the protocols going in, you know, it was never a problem with putting on the gloves, et

[46] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[47] Travis Chi Wing Lau, interview by author, August 16, 2019.

[48] Alida Boorn, interview by author, August 7, 2019.

cetera."[49] Likewise, hard of hearing archivist, Michelle Ganz, discussing access in archives stated:

> I've been very fortunate than any place I have done research or have worked at has been very willing to accommodate me with the few accommodations that I need. And most of my accommodations revolve around a phone that can be turned up really loud and understanding that I am a very loud person. Like when I was setting up this meeting that we're having right now, I actually emailed a bunch of people in the office to find a spot where I wouldn't be disruptive and the deal was that I could sit in this office, but I have to work really hard on using my inside voice.[50]

Yet, as disabled lawyer Lili Siegal noted, "I think it's hard for me to say if I felt welcome because every archive that I've entered, I've entered with a certain amount of status: I've been a student or I'm a lawyer or a researcher or, you know?" She continued, "And I was seen as a person who had a right to be there. I was treated pretty well, because I was with Karen [a professor]."[51] And disabled non-binary scholar, Jess Waggoner articulated how financial constraints and the privilege of archival access impact wanting to be *perceived* as grateful:

> Especially if you are an early career scholar or a graduate student and you are awarded a grant, you feel very grateful and you don't want to do anything that would make you seem ungrateful. So from the get go, there is a pressure to hyper perform and to seem to appear as invested in rigor as you can… the idea that you should be at the archives at its

[49] Alida Boorn, interview by author, August 7, 2019.

[50] Michelle Ganz, interview by author, August 14, 2019.

[51] Lilith Siegel, interview by author, August 23, 2018.

> opening and be there until it closes and you need to be there at each day that you said that you would be there in your grant application. And some archives with grants really check in about that and some don't, but you're not really going to know who will be policing that and who won't. So if you have chronic pain or chronic fatigue, this is a really difficult standard to uphold. I didn't want to be interpreted as ungrateful.[52]

Waggoner's words highlight how one's perception of how they are viewed in archival spaces produces an internalized pressure—one that, in contrast to the many disabled people not able to use archives, can produce anxiety around how they are perceived to utilize their archival access. Participants, noting how many disabled people do not have access to archives or other academic institutions, foregrounded their many privileges in being able to do archival work. While some described themselves as lucky to have an assistant or to be able to navigate spaces, others describe how just having institutional affiliation allowed them access to archives. Acknowledging this privilege and being grateful for access to archives, as Waggoner describes, also places a certain amount of pressure on disabled researchers in wanting to take full advantage of that privilege. This first finding illuminates an affective background of anxiety that disabled people feel when being in archival spaces—an awareness of how many people cannot use these spaces while they can alongside a concern about being interpreted as ungrateful.

[52] Jess Waggoner, interview by author, August 16, 2018.

Finding 2 (Some) Logistics of Archival (In)Accessibility

Finding 2.1 Spatial Access

At a fundamental level, interviewees described the difficulty in accessing the physical spaces of archives, highlighting basic physical access for those with mobility-related disabilities. Honisch described, "My own sort of more limited experience actually going to local archives myself, and libraries, which for various reasons, has proved tricky, because I use a wheelchair. And so moving around and within an area or space or being able to position myself, even something as seemingly small-scale as being able to position my wheelchair close enough to the table that I can read through a folder of newspaper clippings or a fairly delicate folder of some sort."[53] Ganz stated the resistance to accessible changes in archival spaces that she's experienced, remarking, "I pointed out that our museum was built in the early seventies, and it had a rotating gallery on the second floor, which was only accessible through two flights of stairs. It was almost 30 stairs to get to the second gallery. And when I pointed out that when the building was built that wasn't an issue but it's an issue now and we could get a chair lift, and they didn't want to fix the problem because that meant that they had to acknowledge that it was a problem."[54] Similarly, disabled undergraduate student, Megan Suggitt mentioned, "I also felt like the documents are inaccessible: you have to climb up the stairs to get to the room and there's no elevator there… they're kind of just hard to find in general."[55] Basic access, especially for those who use a wheelchair or cannot physically navigate stairs, was lacking in many archival spaces that interviewees visited.

[53] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[54] Michelle Ganz, interview by author, August 14, 2019.

[55] Megan Suggitt, interview by author, July 6, 2018.

Additionally, archival research felt inaccessible due to the spatial ways in which archival work is often done; many illustrated the constraints of reading room spaces and the physical toll of archival research. Waggoner, for one, outlined:

> So your body's automatically positioned in these particular ways. And if those are positions that exacerbate pain, then you're just going to be in pain for two weeks. So for me, those were some of the main issues. And I also have colleagues that I can direct you to who have had other issues around access conflicts in terms of blindness in the archive, being chair user in the archives, et cetera. But mine have primarily revolved around chronic pain and hunching over materials and not being able to put the materials where I need them to be for me to comfortably engage with them because they are such rigid notions of how the materials [should] be placed and who should be handling them.[56]

Siegel highlighted, "One [inaccessible] thing is that even to go get the boxes into the room where they're kept was hard, so Karen [her professor] had to do a lot of that, even at Berkeley [an archives which has a disability history collection]."[57]

Siegel described how the UC-Berkeley archives' policies were restricting, "You are not allowed to bring your laptop [so] there's no easy way to get back to where you were [in your research] once you're done [for the day and want to return to where you left off],"[58] while disabled graduate student Cody Jackson pointed out inaccessibility of archival spaces through other archives' policies, "At the Ransom Center, they didn't let you have drinks in there, which I

[56] Jess Waggoner, interview by author, August 16, 2018.

[57] Lilith Siegel, interview by author, August 23, 2018.

[58] Lilith Siegel, interview by author, August 23, 2018.

totally get it—some of us were handling very very old material. But for me, for instance, my mouth gets very dry with my medicine and with social interaction… so for me, I had to keep walking back outside, [then back] inside to get drinks cause my mouth would just get constantly dry."[59] He continued:

> Another example would be that they limit you to like one folder at a time. And so I'd have to go out, I'd have to walk back and forth to this table. And for me *physically*, that's not a problem [but] *cognitively* it is because it takes my focus away. But for a lot of people or disabled people who have physical or mobility issues, I think that would also be a problem because going back and forth, back and forth is not conducive to focus or accessibility.[60]

Participants also spoke about the accessibility issues of not only being in archival spaces but also getting to them. Honisch described not being able to travel to conduct archival research, "I did a whole bunch of preliminary research mostly from a distance in terms of interacting with archives because of my own situation as a disabled person, long distance travel poses a bunch of challenges."[61] And others noted how academic spaces often exclude disabled people, due to financial constraints. Lau described how his archival research was limited:

> Due to the nature of my disabilities and my sort of financial limitations I couldn't go do too much archival work, but I went to the Wellcome Library in London and the British Library as well as spent a little bit of time at the Clark Library in LA, where I had done

[59] Cody Jackson, interview by author, July 5, 2018.

[60] Cody Jackson, interview by author, July 5, 2018.

[61] Stefan Sunandan Honisch, interview by author, July 18, 2018.

some undergraduate work. So I wasn't able to do too much… archive work for very long. I was there for maybe a few weeks, and I coupled it with a conference trip.[62]

Along these lines, Suggitt described how due to the limited hours of operation, she felt pressure to work long stretches of time, “I spent three hours at least just sifting through these documents until they [the archives] closed, because the room is only open for three hours, like once or twice a week. So it's really awful to access it, and you have to make an appointment and that's what I mean, like it's really inaccessible.”[63] Disabled community activist and author Corbett OToole emphasized her lack of access to academic spaces because of institutional affiliation remarking, “I don't even know now that I could get in [to the UC Berkeley libraries and archives] because I don't have a Cal ID… to find information that's maybe not technically behind a firewall but functionally is behind a firewall. So I have a kind of patched together a history.”[64] Such quotes illustrate that disabled archival users experience barriers to accessibility not only at a fundamental level—of physically being able to get into a building or archives room—but also through archives' policies and the ways in which archival research is expected to be done.

These barriers are necessarily unique to disabled people—many people face financial limitations, struggle with hours of operation, and/or lack academic affiliation necessary to use certain archives. However, these aspects are exacerbated for disabled people because of the ways in which they navigate other systems of oppression that compound such issues: from the ways in which disabled people likely to experience poverty, struggle with obtaining a job that

[62] Travis Chi Wing Lau, interview by author, August 16, 2019.

[63] Megan Suggitt, interview by author, July 6, 2018.

[64] Corbett Joan OToole, interview by author, July 17, 2018.

accommodates their access needs, and also have other prioritized expenses such as caregivers, medical bills, and technology repair;[65] the physical, mental, or cognitive ways in which they may not be able work for stretches of time while also having to navigate other time-consuming systems (like finding accessible transportation); to the ways in which they are and have been excluded from academic spaces—Black disabled children, for example, are more likely to be under-diagnosed and over-punished in primary and secondary education,[66] which impacts the ability to continue and participate in higher education and have academic affiliation, to name a few.

Finding 2.2 Digital Access

Due to the inaccessibility of archival spaces—and financial and spatial ways in which disabled people access materials—many interviewees noted the value of digitized materials. Honisch noted, "What I've found as a disabled researcher is that the move towards digitization has been important in ways that sort of go beyond convenience and actually become very much about accessibility."[67] OToole echoed, "digital is everything now because the blind people can access it, deaf people can access, to the people with mobility [related disabilities].... I know that there's some kinds of [chronic health conditions] that are electronics-related, but the number of people who get included in digital sources versus excluded is to me, the best of the options. And

[65] American Psychological Association, "Disability & Socioeconomic Status," https://www.apa.org, accessed June 29, 2020, https://www.apa.org/pi/ses/resources/publications/disability.

[66] Myles Moody, "From Under-Diagnoses to Over-Representation: Black Children, ADHD, and the School-To-Prison Pipeline," *Journal of African American Studies* 20, no. 2 (June 1, 2016): 152–63, https://doi.org/10.1007/s12111-016-9325-5.

[67] Stefan Sunandan Honisch, interview by author, July 18, 2018.

not having that to me is really the crisis of the moment."[68] She also remarked on the wider system issue of disabled people needing free and online sources:

> What to me is a huge part of the challenge is [that] a few disabled people or people connected to disability communities move into academia or are able to be sustained in academia long enough to have positions of power to make change. I don't see these as archival issues, they were bad a hundred years ago, I think they're going to still be bad a hundred years from now…. One of the arguments I make about community scholars is we're really, really dependent on free sources and free internet sources.[69]

Accessing digital materials, however, comes with its own barriers. Honish described how, "I was able, for example, to have some friends of mine—at the time they were in Europe—and so they were able to visit one or two archives on my behalf and send me impressive amounts of digitized materials from these archives [but] the process of securing permission to use these materials in our research became a fairly lengthy and complicated process."[70] OToole described the lack of access to both physical and digital materials: "One of the saddest things to me was that The Lesbian Herstory Archives had an original collective member who was a disabled woman who walked. And yet when they bought a building, they bought an inaccessible building, and they don't have their collection online so I can never go." Siegel remarked, "I know that more and more things are being put online, and I have mixed feelings about that. Because I think it might be a net positive in terms of some types of access but I do also think that there's

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[68] Corbett Joan OToole, interview by author, July 17, 2018.

[69] Corbett Joan OToole, interview by author, July 17, 2018.

[70] Stefan Sunandan Honisch, interview by author, July 18, 2018.

something that's lost when you're not able to be in a physical space and be able to touch things and look at the real thing."[71] As these interviewees described, digitized materials can increase access for people not able to travel or visit physical archives, which can increase access for many disabled people. However, allowing digitized materials to solely replace inaccessible spaces neglects the value of physical accessibility—as Siegel remarks, digital materials, although increasing access to archival work, are not equal to the experience of physically handling records. While digitized materials can open up access for those who are unable to travel or who utilize technological facets to access, like image descriptions, this data shows that digital material is not a substitute for physical access.

Access to archival research wasn't only dependent on spatial and digital access; these interviews also demonstrate that language and how collections describe materials also impact how disabled researchers locate resources. Especially as many researchers try to look at online materials first in attempts to find out the physical holdings of an archives, language and descriptions—or lack thereof—also impacted access to our histories. OToole articulated that in her research, "it was about not being able to find consistent sources. And again, the thing with the Cal archives, like when I was looking at the newspaper articles, I thought, oh, I'll just [search for] 'disability,' 'handicapped,' 'cripple,' 'deaf,' 'blind,' it was just chasing fucking rabbit holes, you know, and, and not even finding anything, like: nope, no results, no results, no results, no results, no results."[72] Similarly Jackson described, "Within traditional archive spaces, I think if you don't get the right keywords into search, it's very hard to find these things…. I think there's a lot of work going on to improve that, so I don't want to pretend that there's not a lot of people

[71] Lilith Siegel, interview by author, August 23, 2018.

[72] Corbett Joan OToole, interview by author, July 17, 2018.

trying to make the metadata more accessible, but in my experience it's not been very accessible."[73] Lau posited that, "Maybe it's because disability studies is still sort of coming into its own, but I still think about how rarely I've actually seen the word 'disability' as an organizing category for a lot of the archives that I've looked through."[74] Likewise, OToole highlights the impact of the lack of descriptive properties, noting how she found materials on disability that were not named as such, "I was both angry and really, really sad that at the casual erasure of my community of people and then anybody who comes to that museum and sees any disabled person who knows that can be, those communities are going to have that kind of similar like 'Yay... Oh... Um,' but also that now the historical record on those objects, you know, going forward is tied to, so you could never find those two pieces of sculpture because they don't exist in a disability context."[75] And Dr. Therí A. Pickens, an Full Professor of English, reflecting on her research and not being able to find disability in history, emphasized:

> I was like: *I was right*. People do call this by other names. It is possible to envision a world where these things aren't said outright, but are experienced. And, what does it look like to have a different vocabulary for this and not one that erases the reality or even attempts to flirt with ignoring the reality, but one that embraces it wholesale, that carries a different etymological or cultural lineage than that which we already see in either public parlance for academic discourse about disability.[76]

[73] Cody Jackson, interview by author, July 5, 2018.

[74] Travis Chi Wing Lau, interview by author, August 16, 2019.

[75] Corbett Joan OToole, interview by author, July 17, 2018.

[76] Therí A. Pickens, interview by author, September 6, 2018.

While many interviewees described how digital materials could facilitate navigating some accessibility issues, digital archives were not a substitute for spatial exclusion. This finding illustrates some experiences of navigating inaccessibility and, more importantly, descriptively shows the overwhelming prevalence and various instances of inaccessibility.

Finding 3 The Affects of (In)Accessibility

The first two findings, which demonstrate feelings of anxiety around being able to use archival spaces alongside their staggering presence of inaccessibility, lay the foundation for more deeply investigating the affective impacts of archival in/accessibility. The physical location of archival spaces, how materials are treated, and how disabled researchers could access materials all had affective impacts on disabled archival users. Location and accessibility of materials impacted how disabled people felt regarded, valued and cared for, and these informed other researchers' regard for the disabled. More specifically, disabled people were often hard to locate in archival material, which impacted disabled researchers as they were looking for a connection to disabled histories and often could not find them. This bias also impacted how individual researchers felt about themselves being in archival spaces, which shaped their sense of belonging. Affects such as a sense of not being valued, being "part of the trash," deprioritized, and erased all emerged as significant experiences of unbelonging and often feeling out of place in archival spaces.

Finding 3.1 Material Affects

The physical locations of archives and accessible entrances have a deep emotional impact on disabled users' perception of how disability is understood and valued in academic institutions.

Suggitt remarked on how materials on Huronia Regional Centre were difficult to physically locate, as they were kept in a separate—and inaccessible—room within the archives:

> I really feel like they are hidden. I had to ask specifically for the Huronia Regional Centre records… and even the lady that was working that day that I went up to, she's like, oh 'those are usually kept in the back. No one usually asks for them.' So that was really surprising to me—most of the historical records that are in the archival room are mostly things on Orillia [the city where the centre is located] and [local] agriculture, family history, schools, the census documents. But when it comes to Huronia Regional Centre, it's tucked away where no one can see, no one knows about them. I honestly would say I don't think anyone except for me and the survivors would really go to that room to actually research Huronia Regional Centre. Because when I mention it to people in Orillia they have no idea that the building was a former institution.[77]

Segal made note of a similar spatial situation in researching disability history and how an archives' location might impact how disabled people find that history: "they [the archives] are made to be these places that are supposed to be somewhat separate from the rest of campus…. Often you go down the six hallways and then down this ramp and around like around somewhere. And why is this archive tucked away and what are some of the access implications of that? And also I do think it doesn't apply to me so much—it would be super hard to use these archives if you had any sight-based problems." Even if spaces are physically accessible, the implementation of accessibility informs how disabled people feel valued by institutions—these quotes illustrate how disabled people feel devalued by the locations of archival materials on

[77] Megan Suggitt, interview by author, July 6, 2018.

disability and the challenges of being able to find them. The physical locations of not only the archives themselves but also the accessible entrances also speak volumes to how disabled people feel respected/understood/prioritized by an institution. Pickens, for one, described the affective impact of accessible entrances—in academic institutions, broadly—frequently being located not only in separate areas but often near loading docks and trash pick up areas:

> Somebody said something to me about access to one of the current science buildings, and I was like, 'oh, you mean where the trash cans are?' And I got a couple of blank stares and a few puffs and sighs of indignation, and I wanted to be like, no, 'there's nothing that reminds me more that I am part of the trash at the institution than being told that my entrance is where the trash is.'[78]

She continued, drawing throughlines with disability and racial segregation: "I teach in the oldest building on campus, which means that the stairwell allowed for you to retrofit an elevator in there, and when I teach Jim Crow, I am always reminded that I have to enter through the back of that building. What must it feel like for me as a Black woman to enter through the back of a building and then go in there and talk about separate but equal water fountains and bathrooms?"[79] Pickens highlights not only the parallel histories of racism and ableism but also how the two converge for her as disabled Black woman in navigating academic spaces—the location of accessible entrances echoes the devaluation of disability, one that parallels and overlaps with histories of racism. Even though buildings are physically accessible, disabled people still feel devalued, "part of the trash," which shapes their experiences in spaces.

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[78] Therí A. Pickens, interview by author, September 6, 2018.

[79] Therí A. Pickens, interview by author, September 6, 2018.

OToole remarked on the inaccessibility of archival collections at Berkeley and subsequently feeling erased through such physical and digital inaccessibility. “One of the huge fights I'm having right now with Cal [UC Berkeley] is the Cal archives, they don't want to collect disabled people's history and they refused to digitize it. Wow. And I'm like, ‘if you don't digitize our history, *we don't exist*,’ you know? [The archives responded] ‘Well, they can write a letter and say that they want to do a research project and they can come to Cal, and we'll pull the boxes for them.’ Right. That's not accessible to so many people. Literally that's all they're offering.”[80] These quotes surface some of the affective impacts of inaccessibility of archival spaces: how hidden or difficult to access archival spaces produce a sense of feeling not only deprioritized but also erased, “that we don’t exist.”. Both the locations of materials that document disability history, the placement of accessible entrances, and the availability of digitized materials tell disabled people how they are valued (or not) by an institution.

This sense of value, as Lau illustrated, can have potential impacts for first-time disabled archival visitors:

> What I think is the case in many archives is that accessibility training and accessible pedagogy is not a priority or it's often framed as, ‘oh, that is that the particular need of that class,’ rather than a universal design concept where it's like, ‘how do we maximize accessibility for all students that come in here,’ many of whom have never been are like me and feel alienated by it. If this is the one opportunity an undergraduate student has to enter the archive, this is the time, yet again, to put disability first, but—maybe it's resources, maybe it's training—but that's not what happens unfortunately.[81]

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[80] Corbett Joan OToole, interview by author, July 17, 2018.

[81] Travis Chi Wing Lau, interview by author, August 16, 2019.

Inaccessibility can produce a sense of alienation that is deeply tied to a sense of belonging in an academic institution. Honisch expanded on such affective impacts of the accessibility of spaces, highlighting the subtlety of exclusion:

> The archivists and people in charge of special collections are and so forth were extremely helpful, once I made it known that I might need help accessing certain materials…. so in that sense, I wouldn't describe my experiences as a straightforwardly negative in the sense of, you know, feeling like certain things weren't available to me or possible for me as a disabled researcher. But I guess what it did is sort of bring me to an even deeper awareness of what it means to be a disabled researcher in a physical space that *doesn't necessarily exclude a disabled body in overt ways, but it wasn't necessarily designed with that experience in mind.*[82]

While inaccessibility might not be 'obvious' to some, the subtleties of inaccessibility also produce a sense of alienation and can bring deeper awareness of oneself in a space. Pickens remarked on the emotional toll it takes to name inaccessibility, "So naming it when it's not outrightly named as such or calling attention to it when it appears that it's sort of floating there and no one wants to deal with it is, it's costly. It's expensive, *it's emotionally expensive*."[83] These quotes illustrate some of the ways in which physical spaces of archives and the ways that accessibility is implemented inform how disabled researchers feel included, excluded or perceive how disabled people are valued by an institution.

[82] Stefan Sunandan Honisch, interview by author, July 18, 2018.

[83] Therí A. Pickens, interview by author, September 6, 2018.

The physical locations of archives and materials on disability affectively impact disabled archival users, but also the ways in which materials were treated greatly informed how disabled people felt valued. OToole demonstrated the importance of having materials on disability, stating, "For disability groups, which is most disabled people who don't have those kind of community histories or who's people—like people with down syndrome—who haven't been allowed to have access to literacy, [or are] undocumented, documenting their own communities, that stuff is like so hard to find because you have to find a '*why would somebody care enough to write it down*?'"[84] Suggitt remarked on seeing materials stacked in the windows of the now closed asylum, "I went for a tour with the Huronia survivors. You look in the windows, you can still see file folders on the desks. So I feel like if they actually did clean out all the documents and made those documents accessible and acknowledge those documents, then the collection would be upkept and you would be able to access legitimate information."[85] Yet, in contrast, she described how the materials that have been accessioned into an archive are treated: "I just got handed the box like, 'here you are.' And it was just really frustrating. It was just literally in like a little shoe box and it was just awful, I just couldn't believe it."[86] Waggoner articulated how they feel when they handle materials that have not been cared for, "I feel like when I literally have a material that's disintegrating and my gloves, I feel like that history is disintegrating, that *care* is disintegrating, whenever it was. And so there is this material relationship to the archive when… there's no attempt to preserve something…. I think that access, a true attention to accessibility, is just as important to me as a like cognizance of or a presentation of your disability archive." The

[84] Corbett Joan OToole, interview by author, July 17, 2018.

[85] Megan Suggitt, interview by author, July 6, 2018.

[86] Megan Suggitt, interview by author, July 6, 2018.

structural and material ways in which accessibility is implemented and materials are treated greatly impact how disabled researchers feel disabled people are often not valued or prioritized.

Finding 3.2 Affects of Archival Use & Personal Belonging

Adding to how the ways that accessibility is implemented (or not) in archival spaces, another theme that emerged was how interviewees regarded themselves physically being in archival spaces—how disability in general was treated informed their personal levels of comfort in navigating archival research. Many disabled archival researchers described an awareness of how they were perceived in archival spaces—often feeling out of place. Ganz described her concern around being perceived as disruptive when working with audio collections and how she preemptively apologizes for potential disruptions:

> I do worry a lot, especially when I'm dealing with collections that have audio, because even before I had the hearing aids, even if I was using headphones, I'd have to start turning them up so loud that the noise would bleed out and cause issues in quiet areas. Or there'd be situations where I didn't realize that the headphones had come unplugged and that that everybody could hear—I assumed it was just me—so, you know, so being very disruptive and reading rooms…. When I go to a reading room I have a little spiel on like, 'so just so you know, I may not hear you if you're talking to me unless you tap me on the shoulder,' and I start to go through a little thing of, you know, 'here's what's going on and, and almost like apologize in advance in case I'm disruptive.[87]

[87] Michelle Ganz, interview by author, August 14, 2019.

Lau remarked on his perception that, "you're there to use these resources out of the goodness of this archives' heart and you're there to do your job and get out. And it didn't feel like a place of exploration. It didn't feel like a place where I can make mistakes, I could accidentally mishandle something or ask for something that I needed. You could pull something, but in fact you didn't make a request to a librarian. You just did it online and then the number would appear and it felt very depersonalized."[88] He continued, describing the impacts of feeling out of place, "I sometimes ask myself why I'm not more of an archive heavy scholar; my instinct is not to do archival work. My leanings are very theoretical, and I think it's also from these experiences where I feel like the archive is often a financially and physically inaccessible space and a place where I see myself as a burden… I feel like, 'Oh, I'm requesting these things that they don't want to have to dig up.' And I think that that feeling of being a burden *is such a defining experience of being disabled in sort of any institutional space*."[89]

Pickens characterized the complexity of all of these accessibility issues and the impacts on her sense of belonging in archival spaces by stating,

> Phenomenology, in a Merleau-Ponty sense, talks about what it means to be an objective subject and a subjective object: one who is simultaneously seen and experienced by others, who is also, then, seeing and experiencing…. So that scene is contested and certainly is something I did not fully understand until I was working on the second monograph because of the archive—having that experience of being at these long tables in the Huntington reading room in front of pieces of paper and my laptop, realizing that no one was watching me and yet everyone was aware I was there, aware that I was

[88] Travis Chi Wing Lau, interview by author, August 16, 2019.

[89] Travis Chi Wing Lau, interview by author, August 16, 2019.

> looking at a mirror in this evidence, and it was sort of looking back at me. And that then in 30 minutes or so, I would need to go pee in a restroom that was technically accessible, but didn't meet my needs. [90]

The ways in which spaces are constructed, materials are treated, and access is implemented all inform how disabled people often feel like they don't belong in archival spaces. Lau outlined the complexity of not belonging in archival spaces as a disabled person of color:

> I remember being there and my first reaction was: *I feel like I don't belong here.* And at the time it was very much in terms of race because I was the only Asian person in the room—and my entire class was all white people, even the professor—and I'm like, 'am I supposed to be here? Or is this a mistake?' And I remember *really feeling that*. This was also right around the time when my chronic pain got worse and worse. And then navigating the archive, which involved a number of stairs, a number of really sort of blatantly inaccessible places, I started to realize that maybe I don't belong here physically: my body cannot navigate this space or we're looking at documents and they are arranged in a way that would require me to hunch over for long periods of time or they would not be necessarily magnified in a way that I could see them. And there was no desire to help make that process more accessible. And that I think colored my experience of archives for a very long time.[91]

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[90] Therí A. Pickens, interview by author, September 6, 2018.

[91] Travis Chi Wing Lau, interview by author, August 16, 2019.

For many disabled people, as these building findings have illustrated, navigating the nuances of accessibility greatly impacts feelings of belonging in archival spaces. From the locations of archives or collections on disability, the implementation of accessibility, the ways in which materials on disability are treated, to the ways in which individuals have experienced inaccessibility, discrimination, or exclusion, this research has shown that many inaccessible facets of archives produce a sense of unbelonging. Within the archival spaces—where materials are, as Suggitt points out "are hidden," or up a flight of stairs, where policies do not allow for water, medication, or certain ways of interacting with materials, and where accessible entrances are near the trash cans—as well as within archival materials—where disability is often not an organizing category and the overall absence of materials on disability—this finding shows how we experience a plethora of ways that we cannot access archives and therefore our own histories. Such deprioritization of accessibility, flexibility, and disability produce a profound sense of unbelonging in archival spaces.

Discussion

When reflecting on their own ability to access archival materials, many interviewees prefaced their experiences by describing how they were painfully aware of the privileges they hold in being able to conduct research in archives. Emphasizing certain physical or sensory abilities, knowledge of archival processes, academic affiliation, financial support, or access to assistants, almost all participants remarked on, as Honisch described, "I'm still able to gain access to these materials in ways that blind and deaf researchers for example, might not," or how, as Lau noted, "I'm privileged enough not to have to require a lot of accommodations." With such privilege also comes some anxiety, which Waggoner articulated as, "I didn't want to be

interpreted as ungrateful." This first finding illuminates an affective ambience of anxiety that disabled people feel when being in archival spaces—an awareness of how many people cannot use these spaces while they can, alongside a worry about being interpreted as ungrateful. This finding highlights how the internalized expectation of gratitude is shaped through the charity model of disability, which "is often seen as depicting PWDs [people with disabilities] as helpless, depressed and dependent on other people for care and protection, contributing to the preservation of harmful stereotypes and misconceptions about PWDs."[92] Eli Clare notes how through this model disability "must be tempered or erased by generous giving."[93] Access, then, is understood as something disabled people *should* be grateful for, which puts more pressure on disabled researchers to perform gratitude for the access they receive—gratitude is expected of those that do not already belong in archival spaces. This finding also paints the experience of archival accessibility as expansive: when a disabled researcher *does* have access to archival materials, they are drawn to think about all of those who do not, which further emphasizes the community and interrelational aspect of this project as outlined in Chapter Three.

While many participants were aware of their privileges in being able to access archival materials, they also encountered various barriers to being able to conduct research. The second finding highlights and affirms what many disabled people experience in day-to-day life: multiple accessibility barriers. Despite the ADA being passed 30 years ago, many disabled interviewees described the lack of basic access and accommodations to archival spaces, such as multiple flights of stairs without chair lifts or elevators, as well as tables that do not accommodate

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[92] Marno Retief and Rantoa Letšosa, "Models of Disability: A Brief Overview," HTS Teologiese Studies / Theological Studies 74, no. 1 (October 1, 2018), https://www.ajol.info/index.php/hts/article/view/177914, 6.

[93] Eli Clare, "Stolen Bodies, Reclaimed Bodies: Disability and Queerness," *Public Culture* 13, no. 3 (September 1, 2001): 359–65, 360.

wheelchairs. Interviewees highlighted the ways in which archival spaces and archival research can be inaccessible to disabled researchers in more nuanced ways: having to be positioned in ways that exacerbate pain, not being able to lift boxes, policies that may not allow laptops, assistive technologies, water, medications or multiple materials out at the same time, and the various physical and cognitive ways in which research can be rendered inaccessible. Although digitized materials provide more access to broader communities and those who are not able to travel, they still may present other barriers to access. While many interviewees such as OToole noted that "digital is everything now because the blind people can access it, deaf people can access, to the people with mobility [related disabilities]," others such as Honish described the "fairly lengthy and complicated process[es]" to gain permission to digitize. And many cited the difficulty of finding materials online: Lau described, the lack of 'disability' as an organizing category, and OToole noted, the lack of description in general so that a search for multiple terms related to disability resulted little or no findings. And, importantly, digital materials are not necessarily an equal substitute for institutional inaccessibility.

Moreover, this data demonstrates the affective impacts of all of these facets of access—how archival spaces containing materials on disability are, as Suggitt describes "tucked away where no one can see, [and] no one knows about them" or where accessible entrances, located near loading docks and trash cans tell us, as Pickens states, "that I am part of the trash at the institution." Seeing the lack of care—and use—of records on disability inform how disabled people feel valued, as Waggoner describes, "I feel like that history is disintegrating, that *care* is disintegrating." Such accessibility, location, and care all impact how disabled people develop a sense of belonging in archival spaces since, as Lau describes, "that feeling of being a burden *is such a defining experience of being disabled in sort of any institutional space*." Even if spaces

are physically accessible, the implementation of accessibility informs how disabled people feel valued by institutions, feel a sense of belonging or feel as if they are a burden for asking or accommodations. Accessibility, as Honish articulates brings "an even deeper awareness of what it means to be a disabled researcher in a physical space that *doesn't necessarily exclude a disabled body in overt ways, but it wasn't necessarily designed with that experience in mind.*"

This research disrupts the common assumption that since the ADA requires public spaces to be accessible, archival spaces are always accessible to disabled researchers. It highlights not only the limits of the ADA as a rights-based framework that does not serve all disabled people, but also that often the basic facets of accessibility are not even applied to many archival spaces. Furthermore, this data highlights the multiple ways in which disabled people experience inaccessibility in archival settings and that inaccessibility's affective impacts on them—the weight of witnessing the deprioritization of disability in collections, in description, and in access, echoed in disability studies literature: Titchkosky states "people require access to a general *feeling of legitimate participation, meaningfulness, and belonging.*"[94] Disabled, interdisciplinary artist and designer Emily Sara articulates this point as follows:

> Accessibility means a lot more than having a ramp with a 1:12 slope ratio into your space (though we'd obviously really appreciate it if you did have that). Accessibility means that you want us to be there—that we're welcome and we have a sense of belonging. Accessibility means having the representation of mentors that are a part of our community (e.g. did you have any disabled teachers or professors?). Accessibility means

[94] Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning*, 2 edition (Toronto: University of Toronto Press, Scholarly Publishing Division, 2011), 8, emphasis mine.

> not having an entrance that's at the back of the building where you have to navigate past dumpsters and trash cans in order to find a cut curb.[95]

Building on much of the existing literature that both emphasizes how archives affectively impact marginalized communities[96] and that archival spaces sometimes enforce strict—ableist, sanist, and audist—ways of being and behaving,[97] this chapter also emphasizes the subtle ways in which people experience inaccessibility outside of ADA compliance: academic affiliations, hours of operation, surveillance, policies that prevent using laptops, having water, or moving bodies, making noise, or experiencing archival materials all impact the ways in which archival materials are accessible. Additionally it emphasizes the cultural aspects of accessibility, outside of logistics, what Ellcessor describes as, "not an attitude of tolerance or accommodation but an active welcome and recognition of disability as a part of life that brings its own valuable perspectives."[98]

Through these findings, I extend Caswell, Cifor and Ramirez's use of "symbolic annihilation," which highlights how representation (of lack thereof) affectively impacts historically marginalized communities. Chapter Three developed the concept of a *perverse absent-presence*, which complicates symbolic annihilation by drawing attention to how disabled

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[95] Emily Sara, "The White Pube | Art Criticism Etc.," the-white-pube, accessed May 23, 2020, https://www.thewhitepube.co.uk.

[96] Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (June 1, 2016): 56–81, https://doi.org/10.17723/0360-9081.79.1.56.

[97] Jarrett M. Drake, "RadTech Meets RadArch: Towards A New Principle for Archives and Archival Description," Medium, *On Archivy* (blog), April 6, 2016, https://medium.com/on-archivy/radtech-meets-radarch-towards-a-new-principle-for-archives-and-archival-description-568f133e4325#.rxi38ik03.

[98] Elizabeth Ellcessor, *Restricted Access: Media, Disability, and the Politics of Participation* (New York London: NYU Press, 2016), 184, 194.

people "could simultaneously feel the harm of the treatment of disabled people—as well as their misrepresentation and erasure in records—*alongside* a complicated excitement or gratitude for evidence." Building on these sentiments, this chapter further expands symbolic annihilation to consider the affective impacts of not only the contents of archival material, but also the experiences in archival spaces; and these two aspects are deeply intertwined. Affects, or "those visceral forces beneath, alongside," internal, conscious, semi-conscious, or unconscious emotions,[99] are also felt through spatial interactions. One can feel erased through the ways that spaces are constructed, policies are implemented, and materials are treated. And the lack of archival representation, explicit description of disability, digitization of records, and other archival interventions, as this data shows, is reinforced through spatial inaccessibility. The deprioritization of disability both as a subject/organizing category as well as an identity of a possible researcher deeply impacts disabled people's sense of belonging in archival spaces. While accessibility efforts such as retrofitting or altering physical spaces, digitization, and detailed processing require labor and financial investments that archives often lack, the deprioritization of such efforts reflects an affective sense deprioritization, erasure, and unbelonging for disabled people.

And searching for disability where it has not been previously identified and naming inaccessibility comes at a cost. Pickens states, "when it's not outrightly named as such or calling attention to it when it appears that it's sort of floating there and no one wants to deal with it it's costly. It's expensive, it's *emotionally expensive*." I utilize Pickens' words to draw attention to "emotionally expensive" as a term to describe the cost of encountering inaccessibility and navigating archival spaces. This term places focus not only on the affective impacts when

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[99] Seigworth, Gregory J. and Melissa Gregg. *The Affect Theory Reader*. Duke University Press, 2010, 1.

maneuvering archival spaces—the anxiety and awareness of others not able to participate in archival research, the strict ways of being and behaving in archives' reading rooms, the experience of seeing materials on disability not treated with care, and the sense of not belonging—but also the *toll it takes* to move through spaces that aren't' "necessarily designed with [disabled] experience in mind." As many disabled people experience in their day-to-day lives, so many spaces—not only archives but also public sidewalks, apartment buildings, university campuses, and libraries, to just name a few—are still inaccessible on a fundamental level. By drawing attention to the emotional cost of yet another space where inaccessibility is prevalent, I underscore how experiences such as being confronted with inaccessible environments, witnessing the deprioritization of materials on disability, and not being able to access digitized materials are painful, disappointing, and exhausting. This term also circles back to the first finding—the awareness that many disabled people do not or cannot use archives—as well as the limits of this study: due to archival inaccessibility, my sample size is relatively small. While this research is not invested in data that is generalizable, I also recognize all of the disabled people who I could not interview due to all of the ways disabled and other marginalized bodyminds might avoid the emotional expense of being in archival spaces—spaces often designed for white, academic, abled researchers.

These findings resonate with the emerging field of *critical access studies*, which, instead of convincing people of the value of accessibility, starts with the assumption that access is already important. Starting here, critical access studies considers strategies and implementation while also foregrounding a critical lens on systems of power. Hamraie defines critical access studies as a field that "challenges the treatment of access as a 'self-evident' good," and "draws attention to knowledge production as a site in which the structures of everyday life are

redesigned."[100] In their keynote for UD@UAZ Summit on disability and academia, Hamraie emphasizes what makes up critical access studies, asserting the importance of asking questions such as, "Who is the presumed normate user… and then the critical question is what systems of oppression shape our answers to this question?"[101] Critical access studies therefore considers the interlocking systems of power that shape disabled people's life. For example, Hamraie cites the ways in which accessible housing was built around an imagined white disabled user, as well as how accessibility efforts in academic spaces need to also consider the land on which a university sits and its relations to Indigenous communities. In other words, spaces are political and relational.

Hamraie's definition of critical access studies is reflected within the interviews as well, where accessibility is not experienced in isolation. The ways spaces are configured communicate institutional values to disabled people, which is felt through different facets of one's identity. Just as interviewees foregrounded other disabled people who might not have access to archival spaces, so too did they reflect on the ways in which they were perceived through gendered, sexual and racialized lenses. Lau, for example, described feeling like:

> *I feel like I don't belong here.* And at the time it was very much in terms of race because I was the only Asian person in the room—and my entire class was all white people, even the professor—and I'm like, 'am I supposed to be here? Or is this a mistake?' And I remember *really feeling that*…. And then navigating the archive, which involved a

[100] Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (University of Minnesota Press, 2017), 13, 260.

[101] Aimi Hamraie, "Critical Access Studies" (UD @ UAZ summit, The University of Arizona, April 23, 2020), https://drc.arizona.edu/learn/uduaz/summit20.

> number of stairs, a number of really sort of blatantly inaccessible places, I started to realize that maybe I don't belong here physically.

Pickens likewise drew on the complexity of Blackness, gender, and disability: "when I teach Jim Crow, I am always reminded that I have to enter through the back of that building. What must it feel like for me as a Black woman to enter through the back of a building and then go in there and talk about separate but equal water fountains and bathrooms?"[102] These quotes emphasize how access is not just a single-axis identity issue, nor is it just simply logistical, but it is cultural, relational, and inter-informed with other forms of institutional exclusion. This research also highlights a crucial shift from the social model of disability—which places emphasis on discriminatory attitudes and inaccessible built environments—to disability justice frameworks, which not only prioritizes cross-disability solidarity, but the interconnectedness of ableism, racism, sexism, white supremacy, homophobia, ageism, and fatphobia.[103] Given the history of exclusion from academic spaces, what Jay Dolmage describes as "academic ableism," disabled people feel a complex sense of unbelonging through the multifaceted ways in which bodies and minds are assumed to use archival spaces. Returning to the term, "emotionally expensive" then also draws attention to the cost of maneuvering multiple, interlocking systems of expectations and assumptions, how bodyminds are expected to use archives and be in archival spaces, not limited only to disability.

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[102] Therí A. Pickens, interview by author, September 6, 2018.

[103] Patty Berne, "Disability Justice – a Working Draft by Patty Berne | Sins Invalid," June 10, 2015, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne, http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne.

Conclusion

These findings illustrate the multiple ways in which disabled people access or cannot access archival materials. While demonstrating that the logistics of accessibility—such as wheelchair access, flexible reading room policies, digitization, and financial support—is crucial (and need improvement), this research underscores the subtlety of (in)accessibility as well as its affective impacts on disabled archival users. These quotes identify the ways that archives embody certain values around accessibility and those values shape a sense of belonging in disabled archival users. Returning to the title quote from Honisch, archives can produce "a physical space that doesn't necessarily exclude a disabled body in overt ways, but it wasn't necessarily designed with that experience in mind." Echoing much of the recently developed literature on critical access studies, this research has shown how disabled people experience inaccessibility in complex ways that are not limited to just disability—but to multiple aspects of their identity—and not limited to physical archival spaces—but to how materials are treated and described and how spaces are expected to be used.

While adhering to ADA standards of physical accessibility is crucial for increasing access to archives for disabled researchers—as well as disabled donors, records creators, and other community members who contribute to and use archives—much more needs to be done. By drawing attention to the politics of space and the ways in which disabled people can be or feel excluded from archival materials and spaces, this chapter emphasizes a central tenet of crip provenance—the ways in which accessibility is much more than adhering to ADA standards but is also a radical, political, and intersectional imagining of inclusion and the prioritization of disability in materials, policies, and spatial configurations. So, while building ramps and having elevators to archival spaces are essential, archives can still remain inaccessible through

configuring ableist, sanist, audist and expectations of comportment in archives which inform the contextual aspects of records. Moreover, ADA compliance, as Hamraie describes, does little to address other axes of power—they highlight how building ramps for racially segregated schools does little to address racism. Considering the multiple ways in which spaces embody politics, then, can facilitate refiguring more radical concepts of accessibility against the background of the multiple affective ways in which people feel they don't belong in archival spaces.

Encountering inaccessibility and the devaluation of disability in archives is emotionally expensive. To confront inaccessibility not only produces a sense of unbelonging, pain, and anxiety, but also takes a toll. Along with the many academic institutions, public sidewalks, housing, and public transit that remain inaccessible, for disabled people, "that feeling of being a burden *is such a defining experience of being disabled*." Continually confronting inaccessibility—in archives and elsewhere—is painful and exhausting. It is emotionally expensive. As the final facet of crip provenance, this chapter highlights how both the contents of materials and spaces impact how records are located, used, and understood, shaping the context of them in complex ways. To research disability in archives, as I've shown in all of the previous chapters, is to also consider its absence. Therefore, by centering the emotional expense of navigating archival spaces, this chapter highlights disabled users, even in their absence, thus considering the many physical and affective barriers for archival users. It also shows how interwoven the previous three facets of crip provenance are with spaces and accessibility. Not only do spaces have their own histories, land, and materials but also through policies, processes, and processing, influence how disabled people feel a sense of belonging while using archives. People, systems, materials, and spaces—each with their own histories and contemporary experiences—are deeply connected, and a crip provenance allows for expanding what we

consider as part of a records' provenance. Placing focus on accessibility as part of the context of records—which shapes how the content of records is experienced—expands a crip provenance to consider the multiple and interconnected ways in which archives can produce a sense of symbolic annihilation. And although this research focused on disabled archival users, this lens can also be used to think about the barriers and forms of exclusion for disabled records creators, donors, archivists, and other disabled people who contribute to archives.

The aim for this chapter is not to provide solutions to archival inaccessibility but to lay the foundations for the affective impacts on multiple disabled archival users. Highlighting the emotional expense of inaccessibility provides an opportunity to complicate archival realities: through demonstrating the social and built constructs that inhibit disabled people from having equal access to opportunities and resources, this lays a foundation for the necessity of archival interventions. While archives balance heavy workloads of processing materials with the monetary and labor costs of digitization and accessibility, this research shows how the deprioritization of access is an issue of the distribution of material resources. This foundational research could inform archival policies and change the inherent nature of archival spaces so that the relationships with those who have historically been excluded can also shift to become more equitable. Through highlighting how archival spaces impact disabled patrons and content creators, this work could facilitate justifying archives in re/designing their spaces, policies, and daily work to better support research for and contributions from disabled people. Perhaps this chapter could incentivize a closer attention to accessibility and therefore more support for a user group that historically has been excluded from academic and research-oriented spaces.[104] What is more, with a critical access studies lens, archival accessibility could be expanded as a

[104] Jay Dolmage, *Academic Ableism: Disability and Higher Education* (University of Michigan Press, 2017).

collaborative initiative towards multiple agendas—not only through cross-disability solidarity and nuanced frameworks of how bodies and minds can experience archives, but also in tandem with anti-racist, de- or anti-colonization efforts for LAM spaces, policies, and work.

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Conclusion: Disability & Its Absence

This dissertation has examined how we—as archivists, as disabled people, or as researchers—can use archives to tell an intersectional history of disability through complicating and cripping provenance. Responding to my guiding research question of "how can we tell a history of disability when there is partial or even no evidence of disabled people?" I examined the ways in which disability is experienced, represented, or absent in relation to archives. Through two research methods—interviews with disabled people and historical-archival research around the Field Museum of Natural History—I have examined both how records and archives affectively impact disabled people and how disability studies can provide critical lenses to expanding how we read disability in history. This research considers all of the proximal relationships created both through disability as well as archival and museum processes as a theoretical framework to grapple with the erasure of disability in this history to develop a crip provenance. Using disability studies scholarship, which critiques rehabilitative and curative rhetorics, I radically reframed the archival concept of provenance to address the reality of archives: how materials are always already fragmented, dispersed, rearranged and incomplete. Through a rejection of 'fixing' or 'restoring' a fonds—combatting how archivists often work to reconstruct a fonds—a crip provenance emphasizes the *new* relationships created specifically *because* materials have been rearranged, removed, or never were created in the first place. And I looked expansively at how records in proximity to one another today can tell a new story about disability's connections to natural history, colonialism, and archival processes.

Towards a Crip Provenance

This research has developed an expansive theoretical and methodological framework of a crip provenance for considering the intersections of disability and archives. I have critically addressed the directionality of provenance—the emphasis of the origin, history and custody of a record or fonds—in order to illuminate ways of grappling with the erasure of disability in history. Drawing attention to the historical underpinnings of how archivists often work to reconcile with records that have been moved, rearranged, and dispersed to reconstruct a fonds, I have highlighted the underlying 'curative' and 'rehabilitative' orientations of provenance. Put in conversation with disability studies scholarship—which critiques rehabilitating, curing, and restoring—the concept of provenance can be radically refigured, placing less emphasis on 'fixing' or reconstructing a fonds (which might have never been 'whole' in the first place). Instead this research addresses the reality of archival material to acknowledge the new relationships created because they are always already fragmented. Therefore a *crip provenance*—a disability-centered framework that resists the desire to restore and instead meets records where they are at to acknowledge all of the new connections and relations that are created because records are always already dispersed, duplicated, and partial—places foci on the people, systems, materials, and spaces that are in relation to both disability and archives. A crip provenance can not only complicate existing representation of disability in archives but also can draw attention to absences, messiness, and the impossibility of knowing a complete disability history. It considers the connecting histories of records and the people, materials, languages, and systems—expanding outward from a single record or fonds to consider influential, interwoven, and parallel factors—that informed its existence, while also facing forwards—drawing attention to the new connections that are created because records are moved, reorganized, processed, and

experienced at different moments. I view this crip framework as a way to address disability in archival material broadly: to complicate and politicize records that document disabled people as well to connect other records to disability and discuss ableism's intertwinement with other systems of oppression.

Through this framework, this dissertation has shown how we can center disability in history: as disabled people experience records (Chapter Three), archivists accession, describe, process and them while considering how and why they were produced (Chapter Four), archival labor and exposure to toxic materials have parallel histories that can be connected to disability (Chapter Five), and all of those facets are bound up in how spaces are used, experienced, and accessed (Chapter Six). Chapter Three, using data collected through interviews with disabled archival users, demonstrates the affective impacts of representation of disability. Placing emphasis on how living disabled people are affected by representations or the lack thereof, a central piece of a crip provenance emphasizes how materials are experienced and shape how disabled people understand themselves and their identity. By proposing the term *perverse absent-presence* this chapter highlights the dual affective nature of problematic representation and erasure for disabled people: to simultaneously feel the harm of the treatment of disabled people *alongside* a complicated excitement or gratitude for evidence. This chapter demonstrates the necessity for disabled people to see themselves in history and underscores how disabled people can feel a deep sense of community not only with current communities, as a diverse community with multiple intersecting identities, politics, and opinions—which is so vital to our existence—but also with disabled people across time, thus illustrating and developing the term *archival interdependence*.

By drawing attention to the interlocking systems that have historically classified disabled people, Chapter Four emphasizes the subtlety with which disability can be perceived in records. Drawing attention to the power of language and the potential to complicate descriptive properties of records, this chapter expands not only what we can consider as part of a record, but also the assemblage of what we can expand to include in records' description. This chapter builds theory around archival description and shows how a crip provenance can not only highlight the *systems* that produced a single record or fonds, but also all of the interlocking systems that created and influenced the creation of other records, entangled with legislation, archival processes, attitudes, and records across time. This chapter argues that an archival assemblages approach not only facilitates complocating how disability is represented in records but also shows that a disability-centered critique of language can open up contestation of the process of categorization and include such contestation in archival description. Through the ways in which records or objects are created, appraised to be part of institutions, and located within multiple historical and contemporary systems (including archives), this chapter shows how a crip provenance builds a political, contextual, and expansive lens to illuminate the many assemblages that *could* be represented in archival description, while acknowledging that description can never be 'complete'.

Chapter Five grapples with how to discuss disability in history when there may not be much evidence. This chapter builds theory around natural history and utilizes queer phenomenological approaches to draw attention to that which has been accepted as standard practice and thinks through the politics of exposure. Through an attention to materiality—how materials are connected to power, politics, and disability—this framework adds to a crip provenance as it allows us to talk about multiple histories, parallel experiences, and toxic

exposure by thinking about one chemical used in archives, museums, and domestic spaces. By understanding how systems of value become embodied in preservation practices as well as how those practices permeate multiple instances of feminized labor, I've shown how we can consider the history of naphthalene as one about disability and colonialism. As naphthalene is used not only on Indigenous materials, but also insect collections, mammal skins, etc., we can understand a history of colonialism and disability within non-human animals as well. This constellation has allowed for me to talk about a history of disability without explicit evidence of disability in history—through thinking about the ways in which values are embedded within materials as well as thinking about a material's alternative uses, exposure, and movement. Therefore this facet of a crip provenance illuminates not only a history of disability when it is not apparent, but also a method of identifying the subtleties of colonial values that a disability studies lens makes possible.

Lastly, Chapter Six returns to living disabled people's experiences by drawing attention to the politics of space and how in/accessibility impacts how records are located, experienced, or not. Not only do spaces have their own histories, land, and materials but also through policies, processes, and processing, influence how disabled people feel a sense of belonging while using archives. This chapter utilizes Picken's words to propose the term *emotionally expensive* to emphasize the affective toll of inaccessibility: to confront inaccessibility not only produces a sense of unbelonging, pain, and anxiety, but also takes a toll and can prevent disabled people from using, donating, or interacting with archives. As the final facet of crip provenance—which considers all of the relationships that are created because materials on disability are duplicated and dispersed which adds to a records' context—this chapter demonstrates disabled people's relationships to space and place as well as how archival spaces, accessibility, and archival

experiences all add context to records and therefore should be considered as part of provenance. To research disability in archives, as I've shown in all of the chapters, is to also consider its absence. Therefore, by centering the emotional expense of navigating archival spaces, this chapter highlights disabled users, even in their absence, thus considering the many physical and affective barriers for archival users.

Together, these chapters coalesce to show all of the relationships and proximities one can consider when thinking about the history of a record, the subtle ways in which disability can be represented in history, and all the facets that *expand the context of records with disability at the fore*. People, systems, materials, and spaces—each with their own histories and contemporary experiences—are deeply connected and considering contemporary experiences and the spaces that shape them can lead to a complex picture of what is considered part of a record. Furthermore, this research emphasizes not only the impacts of archives and the records they contain but also possible theoretical interventions for archivists, archival users, disabled communities, and the overlaps therein.

Archival and Disability Methodologies

This dissertation, in developing a crip provenance, provides methodological contributions to both archival studies and disability studies. Methodologies provide broader theoretical and analytical frameworks which inform research processes; they are "the logic behind the methods we use in the context of our research."[1] Archival studies is a discipline dedicated to critically understanding how archives operate, preserve perspectives, and influence cultural and individual memory. Archival studies considers not only the theoretical ways in which power operates in

[1] C. R. Kothari, *Research Methodology: Methods and Techniques* (New Age International, 2004), 8.

archives and records, but also the embodied ways in which theories are put into practice through archivists, archival processes, and policies. Similarly, feminist disability studies combines theory and practice, centering on the lived experiences of disabled people to conceptualize the interactions of ableism, racism, sexism, homophobia, fatphobia, and classism and also advocate for political change. Recognizing the deep ties between theory and practice within these two fields, a crip provenance is a theoretical framework founded within archival realities—the WCE records were dispersed, duplicated, and incomplete—and contributes to both theoretical understandings of archival processes and disability as well as practical implications for archival work and disabled experiences. By building from disability studies and archival studies frameworks, this research contributes to both fields through the ways in which it critically draws attention to both disability and archival relationships.

This framework for provenance contributes to the field of archival studies as a way of resisting orienting backwards, letting go of the attachments to a previous whole, and instead creatively intervening. Drawing attention to how many archivists work to reconcile with records that have been moved, rearranged, and dispersed, to reconstruct a fonds, I highlighted the 'curative' and 'rehabilitative' orientations of provenance. And while archival studies scholars have expanded and complicated provenance, others have critiqued the ways in which it can uphold historical inequities.[2] Therefore, building on the critiques of provenance and expanding further from concepts such as societal provenance, a crip provenance resists 'fixing' or 'restoring' a former whole. It instead addresses archival relations and the directionality of provenance—the emphasis of the origin, history and custody of a record or fonds—in order to

[2] Jarrett M. Drake, "RadTech Meets RadArch: Towards A New Principle for Archives and Archival Description," Medium, *On Archivy* (blog), April 6, 2016, https://medium.com/on-archivy/radtech-meets-radarch-towards-a-new-principle-for-archives-and-archival-description-568f133e4325#.rxi38ik03.

illuminate ways of grappling with the erasure of disability in history by expanding outwards. This framework provides an expansive way for archivists to consider a wide range of materials and histories in relation to records as part of provenance, while also providing a critical lens for how to re/introduce disability in records where it is subtle or absent.

Some literature in archival studies has drawn attention to the multiple relationships that are produced through archives. Caswell and Cifor, using a feminist ethics approach where archivists are seen as caregivers, empasize the many relationships between archivists and records' creators, subjects, users, and larger communities.[3] Considering all of the people—such as users, creators, donors, subjects, and archivists—that are in relation to one another through records, a crip provenance framework expands further to consider records in relationship to disabled *people* who experience them; to *systems* that produce(d) records around disability and the archival systems and processes that are embedded within archival practice; to *materials* that can tie histories together and provide expansive ways of centering disability; to *spaces* that have their own histories, politics, barriers, and impacts; and to one another. By bringing a disability studies lens to archival studies—building on archival literature that uses critical theory and critical justice-centered approaches to analyze axes of power[4]—I have demonstrated expansive

[3] Caswell and Cifor's work has also been expanded to include other relationships: Rachel Mattson and Jasmine Jones proposed the archivist-archivist relationship in 2017 and Itza Cabrajal considers the donor-archivist relationship in an upcoming special issue of the Journal of Critical Library and Information Studies on radical empathy. "ARCHIVES 2017: 301 - Radical Empathy in Archival Practi...," accessed July 1, 2020, https://archives2017.sched.com/event/ABGy/301-radical-empathy-in-archival-practice; Michelle Caswell and Marika Cifor, "From Human Rights to Feminist Ethics: Radical Empathy in the Archives," *Archivaria* 82, no. 0 (May 6, 2016): 23–43.

[4] For example, see: Melissa Adler, *Cruising the Library: Perversities in the Organization of Knowledge*, 1 edition (New York: Fordham University Press, 2017); Marika Cifor, "Affecting Relations: Introducing Affect Theory to Archival Discourse," *Archival Science* 16, no. 1 (March 1, 2016): 7–31, https://doi.org/10.1007/s10502-015-9261-5; Emily Drabinski, "Queering the Catalog: Queer Theory and the Politics of Correction," *The Library Quarterly* 83, no. 2 (April 1, 2013): 94–111, https://doi.org/10.1086/669547; Jarrett M. Drake, "Liberatory Archives: Towards Belonging and Believing (Part 2)," *Medium* (blog), October 22, 2016, https://medium.com/on-archivy/liberatory-archives-towards-belonging-and-believing-part-2-6f56c754eb17#.4hky7zcjt; Anthony W. Dunbar, "Introducing Critical Race Theory to Archival Discourse," in *Research in the Archival Multiverse*, ed. Anne J. Gilliland, Sue

ways of thinking about disability in history as well as the ways in which archives and the records they hold are inherently linked to disability and disabled people.

While this framework is theoretical, it can have practical implications for archival work. Anne J. Gilliland emphasizes the impact for records on social justice issues and human rights, specifically, "the role that recordkeeping plays in facilitating or impeding the very real and often crucial need for those who survived these events and their families and communities to be able to move forward with their lives."[5] While "moving past may never be possible" this framework can contribute to archival studies by centering the very real and immediate needs of disabled people—both to shift the ways in which disability is understood through representation and to change archives and archival processes to include and better serve disabled people. For example, Chapter Three, by providing an understanding disabled people's complex relationships with their misrepresentation in archival material, makes a case for archivists to involve more disabled people in archival processes to better reflect our relationships and understandings of history. Chapter Four, by complicating what is considered self-evident in a record, provides a space for archivists to utilize digital tools to provide more complex descriptions of records and to think of ways to connect disparate records to one another. And Chapter Six lays a foundation for

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McKemmish, and Andrew J. Lau (Clayton, Vic: Monash University Publishing, 2017), 382–410; Jamie A. Lee, "Be/Longing in the Archival Body: Eros and the 'Endearing' Value of Material Lives," *Archival Science* 16, no. 1 (March 1, 2016): 33–51, https://doi.org/10.1007/s10502-016-9264-x; Hope A. Olson, "The Power to Name: Representation in Library Catalogs," *Signs* 26, no. 3 (2001): 639–68; Tonia Sutherland, "Archival Amnesty: In Search of Black American Transitional and Restorative Justice," *Journal of Critical Library and Information Studies* 1, no. 2 (June 2017), https://journals.litwinbooks.com//index.php/jclis/article/view/42; Tonia Sutherland, "Reading Gesture: Katherine Dunham, the Dunham Technique, and the Vocabulary of Dance as Decolonizing Archival Praxis," *Archival Science*, May 6, 2019, https://doi.org/10.1007/s10502-019-09308-w.

[5] Anne J. Gilliland, "Moving Past: Probing the Agency and Affect of Recordkeeping in Individual and Community Lives in Post-Conflict Croatia," *Archival Science* 14, no. 3–4 (September 2, 2014): 249–74, https://doi.org/10.1007/s10502-014-9231-3, 252.

archivists to justify accessibility improvements, reassess reading room policies, and allocate funds to processing materials on disability to make them available online.

This research also contributes to methodologies within disability studies by drawing attention to the archival decisions made in the very materials we use to tell our histories. Jina B. Kim defines a "Critical disability methodology: a mode of analysis that urges us to hold racism, illness, and disability together, to see them as antagonists in a shared struggle, and to generate a poetics of survival from that nexus," which decenters whiteness and able-bodiedness/mindedness.[6] That lens has served for disability studies scholars to tell crucial pieces of disability history by focusing on the ways that systems devalue, shape, and document disabled lives and by using records that can serve as evidence of those systems.[7] Not only has disability had a fraught relationship with archives (as archival materials were often produced as a way to identify, control, profit from, and oppress people with disabilities), but also the plethora of these types of records to help us reconcile with a crucial *piece* of disability history, one that has historically enacted violence against marginalized communities. By using archival studies as a lens to think about disability, this research highlights how archival studies approaches assess the granular ways in which values are ingrained in archives: through not only the creation of records, but their accumulation, appraisal, description, and access within physical repositories. Combining these two methodologies within a crip provenance, then, not only allows me to think about the systems of devaluation that produce certain types of records, but also how those values become embodied in and shaped by archives and archival processes. Just as a critical disability

[6] Jina B Kim, "Toward a Crip-of-Color Critique: Thinking with Minich's "Enabling Whom?"," *Lateral* (blog), May 15, 2017, http://csalateral.org/issue/6-1/forum-alt-humanities-critical-disability-studies-crip-of-color-critique-kim/.

[7] Throughout this dissertation I have provided many examples of disability studies scholars who have used records to retell disability history. For another example see: Susan Burch and Michael Rembis, *Disability Histories* (University of Illinois Press, 2014).

methodology makes room to think through the multiple systems of devaluation that produce records that document, control, and contain disabled and other marginalized lives, so too does it make space to think through other omissions—how systems of archival power subsequently impact records, what we can know, and how we interpret records. To expand critical disability studies methodologies to archival work and research is to not only consider what is in or absent from the historical record, but also the multiple layers of past and ongoing decision-making that also imbues absences into the narratives of our past. While this research has used such disability studies lenses as a way to think through archives, it contributes to disability studies by drawing attention to the systems that impact how we understand the very materials we use to tell disability histories.

Absences of Disability & the Archival Grain

Despite the small but growing body of literature around disability and archives as well as the common use of archival materials in disability studies literature, this research draws attention to the representation of disability in records and how it is always partial if not lacking entirely. Michelle Caswell tells us that "Not all events are recorded; not all records are incorporated into archives; not all archives are used to tell stories; not all stories are used to write history."[8] This research contributes to thinking about *archival absences and partialities*: the multiple, often illegible, layers of absences, subtleties, inaccuracies, and perspectives that are embodied in records, archives and the lack thereof through the creation of documentation, archives, archival

[8] Michelle Caswell, *Archiving the Unspeakable: Silence, Memory, and the Photographic Record in Cambodia*, 1 edition (Madison, Wisconsin: University of Wisconsin Press, 2014), 10.

systems, stories, and history.[9] Through addressing the misrepresentation, underrepresentation, and omission of disability in records, and—in response to the need for disabled people to see themselves more complexly in archives—this research develops a framework for reading along, against, and outside the archival grain.

Scholars have drawn attention to the ways in which archival documentation is always already partial, what many have named "the archival grain." Sadiya Hartman, contending with the limits of archives, especially around enslaved women, provides the method of critical fabulation to "imagine what cannot be verified, a realm of experience which is situated between two zones of death—social and corporeal death—and to reckon with the precarious lives which are visible only in the moment of their disappearance."[10] Hartman reads "against the grain" of archival documents to imagine how we can understand archival subjects outside of dominant narratives of violence, and offers this method as a way to think through the re/presenting of lives through the process of narration. Influenced by Hartman, Marisa J. Fuentes further builds on re/imaging archival narratives by suggesting reading "along the biased grain." This method, she explains, is intentionally utilized to both provide narratives counter to what has been documented by those historically in power (as embodied in archives and archival records) but also to allow the reader to have their own interpretation of material. Fuentes demonstrates this through the

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[9] Although other scholars have referred to the same or similar phenomena as 'archival silences', I use the terms archival absences, omissions, and partialities to avoid potentially audist presumptions and a prioritization of verbal communication.
Lauren F. Klein, "The Image of Absence: Archival Silence, Data Visualization, and James Hemings," *American Literature* 85, no. 4 (December 1, 2013): 661–88, https://doi.org/10.1215/00029831-2367310; Michelle Caswell, *Archiving the Unspeakable: Silence, Memory, and the Photographic Record in Cambodia*, 1 edition (Madison, Wisconsin: University of Wisconsin Press, 2014); Saidiya Hartman, "Venus in Two Acts," *Small Axe* 12, no. 2 (2008): 1–14; Saidiya V. Hartman, *Scenes of Subjection: Terror, Slavery, and Self-Making in Nineteenth-Century America*, 1 edition (New York: Oxford University Press, 1997); Gayatri Chakravorty Spivak, "Subaltern Studies: Deconstructing Historiography," in *Selected Subaltern Studies*, ed. Ranajit Guha and Gayatri Chakravoty Spivak (OUP USA, 1988), 3–32; Michel-Rolph Trouillot, *Silencing the Past: Power and the Production of History*, 1St Edition edition (Boston, Mass.: Beacon Press, 1997).

[10] Saidiya Hartman, "Venus in Two Acts", *Small Axe* 12, no 2 (2008): 12.

robust archival documentation of Rachel Pringle Polgreen—an "extraordinary" and ostensibly hypervisible archival representation—to draw attention to how even seemingly thoroughly documented narratives still need critical examination. By shifting focus onto the women whose labor Polgreen owned, Fuentes reexamines Polgreen's success and power and draws attention again to archival absences.[11] As much archival material is produced by and mediated through those in power, it is necessary to look for subtexts, absences and obscured histories to construct more complex counter/narratives.

Building on such works within Gender Studies and Women of Color Feminisms and with an attention to disability as a political and contestable category, this dissertation reads not only against and against the biased grain, but also outside of the archival grain. It first offers a critical reading of *the documentation of disability that is legible*, against the (biased) grain. Chapter Four, using an assemblage approach to archival description, destabilizes what is thought of as self-evident in a record to surface alternative contexts, histories, systems, and affect of archival material. A political/relational approach helps to move away from the replication and reliance on self-evident properties of a record and then supports addressing, not redressing, contestable terms, both of which illuminate the archival assemblages which produced it. Like Fuentes, this work mines "archival silences [while also]... pausing at the corruptive nature of this material."[12] Considering the abundance of records—records such as asylum documentation, police records, newspaper articles, and medical records—produced about disabled people, this research

[11] Marisa J. Fuentes, *Dispossessed Lives: Enslaved Women, Violence, and the Archive* (Philadelphia: University of Pennsylvania Press, 2016).

[12] Marisa J. Fuentes, *Dispossessed Lives: Enslaved Women, Violence, and the Archive* (Philadelphia: University of Pennsylvania Press, 2016), 5.

considers how documentation of disability can help us retell a violent history while also problematizing the ways in which biases are ingrained within it.

Second, this framework supports a critical reading of *what is not there*, what also might be considered against the grain and against the biased grain. Chapter Four highlights the partial ways in which disabled people can be represented. Using the World's Congress Auxiliary circular as an example this chapter showed how a political/relational archival approach helps me recognize that the lives represented in each session of the circular are connected to each other, as a body of evidence of the violence endured by those incarcerated, and to a larger cultural climate that encouraged the incarceration and labeling of disabled people. And Chapter Five, by drawing attention to materiality, traces the histories that produced preservative chemicals and museum standards. This chapter shows that crip provenance has a broad scope and can not only function as a way for complicating records that contain disabled people but also be a lens for detecting disability when it is absent. A disability studies lens helps me locate a largely unspoken dynamic and identify discourses around disability: how museums are debilitating and disabling their workers in order to preserve their collections. Through an attention to the history of the development of museum processes and colonial ideals, contemporary systems and processes can be historically situated and their politics illuminated.

Lastly, this framework lends itself to reading disability into history entirely *outside of the archival grain*, as an expansive way of looking elsewhere. David T. Mitchell and Sharon L. Snyder state, "the problem of the representation of disability is not the search for a more 'positive' story of disability… *but rather a thoroughgoing challenge to the undergirding authorization to interpret that disability invites*. There is a politics at stake in the fact that disability inaugurates an explanatory need that the unmarked body eludes by virtue of its

physical anonymity."[13] Chapter Five more explicitly draws out a history of disability when there is no evidence. Through tracing the politics of materiality and investigating parallel histories, this chapter expands the dissertation's framework to consider labor practices, exposure, and how archival, museum, and colonial values are connected to histories of disability. Furthermore, Chapter Three considers how living disabled people—those who are outside of but connected to the archival grain—experience records. Such relationships to records and disabled people across time illuminate how living disabled communities and their interpretations of records are part of what can be considered as part of a record. And their experiences are shaped, as Chapter Six showed, by the archives themselves. A crip provenance, building on reading against the grain—considering archival subjects outside of dominant narratives of violence and within everyday violence[14]—and against the biased grain—reading into what overt documentation cannot give us as well as "the absence of explicit representations"[15]—expands to consider what may be outside of the grain entirely. In other words, this framework functions to talk about two kids of omissions of disability in history. One is hard to describe, but essential: it is the kind of glaring absence we encounter when attempting to research disability in archives, but find nothing. The second is when we do find a disabled person in archival material, but the evidence we find is not just partial, but partial in a way that undermines the person's personhood, autonomy, and agency. And additionally, it functions to consider parallel histories and affective experiences of archival materials and the spaces in which they are kept.

[13] David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2001), 59-60, italics theirs.

[14] Saidiya V. Hartman, *Scenes of Subjection: Terror, Slavery, and Self-Making in Nineteenth-Century America*, 1 edition (New York: Oxford University Press, 1997).

[15] Marisa J. Fuentes, *Dispossessed Lives: Enslaved Women, Violence, and the Archive* (Philadelphia: University of Pennsylvania Press, 2016), 7.

Disabled Archival Users

The empirical research on disabled people as archival users contributes significantly to archival studies, where little research on disabled people as archival users has been conducted. Scholars such as Wendy Duff, Jefferson Sporn, and Emily Herron have shown how the involvement of survivors of state-enforced sterilization in a community-based archive project could reflect an ethics of care and combat symbolic annihilation.[16] Also addressing community-based archives, Chloe Brownlee-Chapman, Rohhss Chapman, Clarence Eardley, Sara Forster, Victoria Green, and Helen Graham have begun to investigate the profound value of disabled people being involved in archival processes to document and complicate historical narratives.[17] However, given the vast amount of records on disability that are located in mainstream archives, or in archives that do not yet involve disbaled people in archival processes, this research addresses a unique area of the affective impacts of representation. Chapter Three builds on Caswell, Cifor and Ramirez's use of Symbolic annihilation—where archival users marginalized by race, ethnicity, gender and sexuality feel essentially erased in history through the ways that they are misrepresented, underrepresented, or not represented in mainstream archives.[18] This chapter, by focusing on the unique experiences of disabled archival users—and also paying close attention to their other intersecting identities—shows disabled people simultaneously feel a sense of violence and erasure through the ways in which disabled people are often problematically

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[16] Duff, Wendy, Jefferson Sporn, and Emily Herron. "Investigating the Impact of the Living Archives on Eugenics in Western Canada." Archivaria 88 (November 17, 2019): 122–61.

[17] Chloe Brownlee-Chapman et al., "Between Speaking out in Public and Being Person-Centred: Collaboratively Designing an Inclusive Archive of Learning Disability History," *International Journal of Heritage Studies* 24, no. 8 (September 14, 2018): 889–903, https://doi.org/10.1080/13527258.2017.1378901.

[18] Michelle Caswell, Marika Cifor, and Mario H. Ramirez, "'To Suddenly Discover Yourself Existing': Uncovering the Impact of Community Archives," *The American Archivist* 79, no. 1 (June 1, 2016): 56–81, https://doi.org/10.17723/0360-9081.79.1.56.

represented in archives, *alongside* a complicated excitement or gratitude for evidence of disabled people in history. This concept of *perverse absent-presence* of disability draws out both the ways in which evidence of disability and its absence can produce a sense of community through the ways in which disabled people politically activate archival materials. Furthermore, this chapter underscores how disabled archival users felt a sense of community with disabled people across time, what I term *archival interdependence*.

Additionally, this research expands Caswell, Cifor, and Ramirez's consideration of archives and affect to not only thinking about representation but also taking into consideration archival spaces. Chapter Six demonstrates how the physical location of archives as well as disability-centered collections within archives, the ways in which archival reading rooms are built, and the ways in which archivists enforce policies of behavior all have the potential to produce a sense of symbolic annihilation. The interviewees expressed how they feel erased through the ways that spaces are constructed, policies are implemented, and materials are treated. While accessibility efforts such as retrofitting or altering physical spaces, digitization, and detailed processing require labor and financial investments that archives often lack, the deprioritization of such efforts reflects an affective sense deprioritization, erasure, and unbelonging for disabled people. This chapter draws out Pickens' words of "emotionally expensive" to underscore how experiences such as being confronted with inaccessible environments, witnessing the deprioritization of materials on disability, and not being able to access digitized materials are painful, disappointing, and exhausting. These findings also resonate with the field of critical access studies and emphasize how access is not just a single-axis identity issue, nor is it just simply logistical, but it is cultural, relational, and inter-informed with other forms of institutional exclusion—expanding the ways in which accessibility impacts

people with disabilities, sick and old people, people of color, and many bodyminds that may not conform to narrow expectations of using and navigating archival spaces. Furthermore, building on archival literature that encourages the participation of the communities who have been left out of archival narratives,[19] Chapter Three and Chapter Six each underscore the need for the involvement of disabled people in archival spaces, processes, and policies to not only perceive and intervene with the representations of disability in records but also with constructing complex and nuanced ways of meeting accessibility. This research emphasizes the importance of elevating more disabled voices in academic spaces, where we historically have been excluded. The unique experiences of disabled people, as described through their voices, shows the powerful contributions that disabled communities can have to shape archival processes, spaces, and the broader field of information studies.

Lastly, this research contributes to complicating digital projects and digitization initiatives both by showing the importance for digitization as a way to increase accessibility for disabled patrons—and other communities who may not have the financial means to travel or visit physical archival spaces—and also to complicate digitization initiatives as purported solutions to physical inaccessibility. Chapter Four, by proposing archival assemblages, posits that digital tools can afford to show a multiplicity of political and relational attachments of records. Digital projects can connect multiple records, systems, and associations that inform how records are understood, complicated, and accessed. And Chapter Six illustrates the importance of making archival spaces accessible through showing the ways in which disabled people navigate, are prevented, and are exhausted by physical inaccessibility. This research underscores the

[19] A. J. Gilliland and S. McKemmish, "Rights in Records as a Platform for Participative Archiving," January 1, 2015, https://escholarship.org/uc/item/5g3135n6; Katie Shilton and Ramesh Srinivasan, "Participatory Appraisal and Arrangement for Multicultural Archival Collections," Archivaria 63, no. 0 (2007): 87–101.

importance of physical and digital accessibility, while also demonstrating that digitization is not a ‘simple’ solution for physical inaccessibility. In other words, while digital technologies can increase the accessibility of records and are necessary investments for archives to create access to wide user groups, investing in physical accessibility initiatives is also incredibly important as they inform how disabled people access and feel valued by repositories.

Future Research

My future research goals are twofold: first, I plan to extend my dissertation research by thinking alongside postcolonial studies and affect theory to further develop articles and a book project. I plan to publish my research on disabled people as archival users in both archival studies and disability studies journals, contributing empirical data to each field on how disabled people use and are affectively impacted by archives. Extending this research, I am currently developing a sibling research project with archivist Veronica Denison, where, using similar methods, we will investigate the affective impacts of archial work and materials on disabled archivists.

My research on the history of the Field Museum and disability will form a book project that builds on my dissertation research to develop archival theory around the history of disability, colonialism, and natural history museums. Providing much needed attention to archival erasure, legacy systems of organization, and contemporary digital tools, it will address multiple museum and archival processes to advance critical readings of disability in history and to build new frameworks of addressing erasure through archival descriptive, organizational, and preservation practices. This book will also draw on information studies as well as science and technology studies to show how contemporary technologies used by archives and museums—while

purporting to increase access and innovate new experiences—can unintentionally embody, replicate, and expand colonial knowledge in digital spheres.

Second, my future research includes a companion project to my academic research: a community-based digital archive entitled, *Disabled Pasts, Crip Futures*. Informed by my conversations with disabled communities, this digital archive will actively digitize materials from disabled people, as to digitally capture complex lived experiences of disabled people and therefore offset the cannon of straight, white single-identity archival representation of disability. In thinking about the history of disabled people, this project also points towards our futures—how a community-driven archive can shape how we want to be understood through records in the future—while embodying the disability rights slogan, "Nothing About Us Without Us." Utilizing my experience in community-centered design and design justice, I will run a series of workshops with a wide range of disabled people to iterate and build a digital platform. Through fundraising, outreach and networking, this community-based digital archive will provide a platform for disabled people to create new records that document our lives and activism today and also describe, redescribe, or add context to existing records. Through building connections with contemporary archives, museums, community organizations, and other repositories, the digital archive will also aggregate existing materials on and about 'disability'—that may not be labeled or described as such. Moreover, in centering crip futurity, the platform will not only provide new ways to see ourselves in archives but also consider the future of the archival profession. By providing disabled communities with training in digital archives and archival processes through a series of paid internships, this endeavor also aims to shape the archival profession: giving disabled people the training and experience to be able to seek future employment in archives and degrees in library and information studies.

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Appendices

Appendix A: Interview Questions

1. How do you prefer to be identified in any work I produce from this interview? If you want your disabilities specified or not.
2. Tell me a little about yourself.
3. What kind of archive were you working in when you found a record(s) on people with disabilities?
4. What search terms did you use to locate records on disability? Did the terms/language used by the archives to describe disability differ from that which you used?
5. What kind of research were you conducting?
6. What was your experience interacting with the archivist(s) at the archive?
   a. Care of collections
   b. Access to collections
   c. How were you treated in the reading room?
7. What is your experience with other archives?
8. When conducting research, were you specifically looking for people with disabilities? If not, what were you looking for?
9. What did you find?
10. How would you describe the quantity of records you found representing people with disabilities?
11. How did you feel when you discovered records on people with disabilities?
12. Can you tell me a story about your experience finding disability in a collection?

. How do these experiences differ from that of your other identities (POC, queer)

13. How do you think records like what you found influence people's understanding(s) of disability?
14. How did this experience compare to how you feel people with disabilities are depicted more generally (outside of archives), for example in media, news, or popular culture?
15. Did you feel as if the ways in which people were described were similar to how you would describe them? How?
16. How did the archival records reflect or conflict with your identity or the way you describe yourself?
17. How does the way you saw disability represented in the past make you feel about disabled people in the past? In the present?
18. Is there anything else that you would like to say or discuss that we have not already addressed or touched upon?

Appendix B: Consent Form

University of California, Los Angeles
CONSENT TO PARTICIPATE IN RESEARCH

The Affect of Mis/representation: The impact of problematic representation in mainstream archives for people with disabilities

Gracen Brilmyer, MIMS (Faculty Sponsor: Dr. Michelle Caswell) from the Department of Information Studies at the University of California, Los Angeles (UCLA) is conducting a research study.

Thank you for your voluntary participation in an individual interview as part of this study. The purpose of this research is to understand the effects of representation/misrepresentation (mis/representation) of people with disabilities in mainstream archives on the disability community. To this end, the interview questions are designed to encourage you to reflect on your thoughts and ideas and articulate your views, opinions and attitudes about your experience working in mainstream archives and finding records that depict people with disabilities.

What will happen if I take part in this research study?
Your participation will last for no more than 90 minutes. Our discussion will be recorded for research purposes and the transcript will be de-identified and stored electronically. The researcher will pose questions that will encourage you to reflect on your identity as a disabled person, the representation of disability in mainstream archives, and the ways in which disability is represented impacts your community.

Are there any potential risks or discomforts that I can expect from this study?
There are no anticipated risks or discomforts. However, our discussion could prompt emotional responses. You may refuse to answer any questions that are uncomfortable or discontinue participation momentarily or completely. You will also not be asked to reveal any information about your disability/disabilities.

Are there any potential benefits if I participate?
You will not directly benefit from your participation in the research. However, your contributions may benefit others in the future.

Will information about me and my participation be kept confidential?
Any information that is obtained in connection with this study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. Although your full name is required to participate, you will have the option to create a unique alias for the purpose of this study and determine how you wish to be identified (or not) in reference to your contributions (see below). In addition, confidentiality will be maintained in these ways: a) A secure network server and password protection software will be used to store data; b) A firewall will be used to protect the research computer from unauthorized access; and c) Only the principal investigator (Brilmyer) and the faculty sponsor (Caswell) will have access to the research data.

What are my rights if I take part in this study?
• You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
• Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.
• You may refuse to answer any questions that you do not want to answer and still remain in the study.
• As the audio of the interview will be recorded, you may review and erase the recording of your research participation if you wish to do so.

Who can I contact if I have questions, comments or concerns about this study?
• **Gracen Brilmyer** (Principal Investigator) at gracenbrilz@gmail.com or
Dr. Michelle Caswell (Faculty Sponsor) at caswell@gseis.ucla.edu or (310) 206-3851.

• **UCLA Office of the Human Research Protection Program (OHRPP):**
If you have questions about your rights as a research subject, or you have concerns or suggestions and you want to talk to someone other than the researchers, you may contact the UCLA OHRPP by phone: (310) 206-2040; by email: participants@research.ucla.edu or by mail: Box 951406, Los Angeles, CA 90095-1406.

Upon request, you will be given a copy of this information to keep for your records.

Do I have your consent to cite you by name?

____ **YES**, you may attribute quotations to me and identify me in scholarly publications (i.e. papers, presentations, posters, lectures).

Please use my:
____ FULL NAME -OR- ____
ALIAS:___________________________________
(please specify how you would like to be identified)

____ **IT DEPENDS** (identify exceptions): ____________________________________

____ **NO**, I prefer not to be identified by name in writing.

What pronouns do you use:

____

SIGNATURE OF STUDY PARTICIPANT

____
Name of Participant

______________________________________ ________________
Signature of Participant Date