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Cover Page Footnote

I would like to thank the editors of this special issue, Jess Waggoner and Ashley Mog, for their work and guidance on developing these ideas and this issue, Michelle Caswell, for her continual advice and feedback, and my disabled communities—near and far—whose writings, conversations, art, ideas and resilience challenge me and bring me so much joy.

Towards Sickness: Developing a Critical Disability Archival Methodology

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Abstract: Although archival records on disability—such as medical, institutional, and freak show records—can facilitate in telling *one side* of disability history, these records often omit the voices of disabled people. Considering the abundance of such documentation as well as how sick and disabled people may be difficult to locate in historical records, this article trains a critical lens on archival absences and partialities. By foregrounding the experiences of sick and disabled writers, activists, artists, and scholars alongside critical disability studies, this article conceptualizes “sickness” to develop a critical disability archival methodology. By illuminating the various ways in which sickness and disability can be unknowable and fluctuating, this article addresses the multiple, often illegible, layers of absences, subtleties, inaccuracies, and perspectives that are embodied in records, archives, and the lack thereof. A critical disability archival methodology underscores not only the multiple systems—social, institutional, colonial etc.—that have produced records about disabled people, but also the granular ways in which such values and absences are also created and embodied within archives and their processes. This methodology therefore provides a framework for both archivists and archival users to work in solidarity with sick and disabled communities in addressing archival representation.

Keywords: archives, critical disability studies, archival methodology, historical research

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Content Notification: This article contains descriptions of the historical oppression of disabled people as well as of the lived experiences of pain, sickness and disability, including misunderstandings, barriers to access, erasure, and ableism.

Introduction

I'll begin with a familiar story, perhaps at the risk of redundancy: during my research at The Field Museum of Natural History's archives in Chicago, I sat in the archives reading room staring at an abundance of absences. I had heard rumors from my disabled community that the museum, one of the largest natural history museums in the US, had featured disabled people in early exhibitions and areas of study. Based on only these rumors, I spent days searching for traces of disability in the museum's history. After scanning pages and pages of documents looking for records explicitly representing disabled people, I was confronted with a familiar, palpable omission. Repeatedly reaching dead ends, I had a conversation with the museum's archivist, and he noted that they *may* have something I would be interested in, after learning more about my research. He later emerged with a scrapbook, made by Henry Field—an anthropologist whose family founded the museum of their namesake—documenting his fascination with a disabled boxer, Maurice Tillet, otherwise known as “The French Angel” (Henry Field Papers). Field's scrapbook contains photos, newspapers, magazine clippings, personal articles, as well as photocopies of

materials that document Tillet's career as a professional boxer and the ways in which his disability was framed in public spectacles. When he was twenty years old, Tillet developed a benign tumor on his pituitary gland that resulted in bone overgrowth and thus an enlarged head, hands and feet. He was depicted as a "gentle giant" in some newspaper articles and as the "missing link" between humans and apes in anthropological studies of his physical appearance and intellectual capabilities. While sifting through the documentation on Tillet, I was acutely aware of not only the abundant omissions in his narratives — the records that document his life were predominantly created by people in positions of power — but also the plethora of absences around other people with disabilities who may have played a part in the museum's history, and history in general, who remain unnamed or illegible in archives.

The scrapbook tells a particular and prevalent story of disability in history, one that valorizes medical science and refuses giving Tillet and other disabled people¹ complex representation. The scrapbook depicts Tillet as a medical anomaly, a stereotypical "freak" through which anthropologists could then make claims about human evolution, emphasizing disability as inferior or less "evolved." And this experience of witnessing problematic and partial representation of disability in archives is not unique nor surprising.² Sick and disabled bodyminds have historically entered into archives and records because of the ways in which disabled people, like Tillet, have been spectacularized through freak shows and similar displays, studied and documented for their differences, as well as policed for being in public (e.g., Baynton 2005; Garland-Thomson 1996; McMillan 2015; Schweik 2010). David Mitchell and Sharon Snyder (2001) state, "the problem of the representation of disability is not the search for a more 'positive' story of disability, as it has often been formulated in disability studies, *but rather a thoroughgoing challenge to the undergirding authorization to interpret that disability invites*" (59-60, emphasis theirs). Grappling with the ways in which archival material on disability is interpreted, this article trains a critical lens on such *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 systems, stories, and histories (Caswell 2014; Hartman 1997, 2008; Spivak 1988; Sutherland 2017; Trouillot 1997; Yeo 2007).³

Responding to the abundance of partial narratives of disability in history, this article develops a *critical disability archival methodology* as a way to confront and grapple with absences of disability in archival material. I build this methodology through combining a *critical disability methodology* — which politicizes disability by focusing on intersectional oppression and the systems that devalue bodies and minds — with *archival methodologies* that center archival processes and decision-making. As methodologies provide a broader theoretical and analytical framework which informs research processes, I desire an archival approach that identifies two kinds of absences and partialities. 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 the archives (like Tillet), but the evidence we find is not just partial, but partial in a way that undermines the person's personhood, autonomy, and agency. I desire an archival methodology that allows for accountability and solidarity with sick and disabled communities without relying solely on their presence in records to be able to tell their stories.

Foundational to this special issue and this article is a critical disability methodology — a methodological approach necessitated by the erasure of disabled people of color — developed by Julie Minich (2016), Jina B Kim (2017) and Sami Schalk (2017) who write towards a "crip of color critique." They call for a "methodological approach to studying power, privilege, and oppression of bodily and mental norms which is **not dependent upon the presence of disabled people**, yet is informed by social perspectives, practices, and concerns about disability" (Schalk 2017, emphasis theirs). Therefore, I conceptualize *sickness* as a way of centering the experiences of sick and disabled people and as a crucial

piece of a disability methodology for archives: to address absences, omissions, and interpretations as well as a way of confronting disabling violences and logics directed toward people of color. In other words, careful consideration of our methodologies when researching disability in history can prioritize solidarity with and accountability to disabled communities. This article asks: how do we⁴ further complicate the absences and partialities within archival narratives around disability, and how might a critical disability methodology help complicate archival approaches and grapple with all that is not represented in archives? I will never know Tillet's experiences, and I know that there are so many stories of disabled people who have never had records made about them, or whose records never became part of an archives.⁵ I therefore want to think through the frameworks of these absences and to think with disabled people in history, like Tillet, who could both experience harm and violence by being subjected to spectacular display, as well as take pleasure, profit from and have agency in their own display and/or their disabled identity.

In this article I weave together archival, historical, theoretical, and personal narratives. I first define how I use the term "sickness" and highlight it as part of a critical disability methodology. Then, I lay a methodological foundation by highlighting how critical disability and archival methodologies can be put in conversation with one another to highlight the multiple systems that produce absences, omissions and perspectives in documentation. Finally, to illustrate and enact solidarity with sick and disabled people, I turn to their experiences by theorizing two major themes from their writings: the unknowable and the fluctuating. In doing so, I further develop a critical disability archival methodology by drawing attention to the granular ways in which absences are produced in records as well as expanding the ways in which we meet those omissions in archives. A critical disability archival methodology, as this article shows, provides a way to complicate the absences within records and facilitates in framing research paradigms, practices, and techniques with the complexity of disabled experiences.

This is an attempt to articulate some of the things we cannot know, how archives and records inevitably tell partial stories and how we — as disabled people, historians, archivists, and/or archive users — can grapple with such partiality through a methodology. Building upon previous work and elevating the perspectives of sick and disabled people, I aim to highlight things that many sick and disabled people know so deeply in our daily lives and articulate them towards an archival methodology. Therefore, by accumulating and synthesizing the throughlines that I witness in so many writings from sick and disabled communities, I aim to mark these as a new form of evidence of our existence while also acknowledging that our experiences vary greatly. Thinking through the records that document Tillet as well as all that is not in the archives — all the records that were never made, those that were thrown away, lost, disregarded throughout their lives before, in and after archives — I outline what feels like just the beginning of what a critical disability archival methodology could be.

Defining Sickness

In developing a critical disability archival methodology, I turn to a wide array of writings from sick and disabled people to highlight and theorize common themes that help in/form archival methodologies and archival practice. To do this, I specifically use the term "sick" because it draws on the complex histories and politics associated with sickness and disability (Ware 2014), intertwined with ableism, racism, classism, sexism, heterosexism, and patriarchy (Berne 2015) as well as embedded in societal fears of contagion and archival systems of documentation.

Sickness is *historical*. As sick and disabled people have a long history of being categorized as deviant, unproductive, undesirable, and/or objects of fear, "sickness" demarcates the messiness and discomfort of how illness and disability have been and are met within society. Susan Schweik (2010)

illustrates how those who were visibly “diseased, maimed, and deformed” were persecuted for being disabled in public, an “imagined contagion [that] combined moral and physical threat” (159). The oppression of sick and disabled people is not limited to the past, but is an ongoing intersectional issue impacted by social and environmental factors, considering, too, how disability, illness, and sickness are also attached to power (e.g., Lee 2020).

Sickness is *intersectional*. Minich highlights (2016) that “disability is disproportionately concentrated within communities of color, which receive unequal health care and experience elevated risk of experiencing workplace injuries” and can be, as Nirmala Erevelles (2011) tells us, “acquired under the oppressive conditions of poverty, economic exploitation, police brutality, neocolonial violence, and lack of access to adequate healthcare and education” (119). Consideration of exposure to environmental toxins (Chen 2017), access to care, hospitals, medical personnel, equipment, and clean water (Kopit 2019; Milbern 2019; Piepzna-Samarasinha 2016; Puar 2015, Wendell 1996) also draws attention to neoliberal notions of productivity, like “ill” and “cripple” (Baynton 2001, 2005). Johanna Hedva (2016) intentionally uses “sick” in Sick Woman Theory to highlight the fictitious binary of sickness and wellness where, “[t]he ‘well’ person is the person well enough to go to work. The ‘sick’ person is the one who can’t.”

All of this is to say that sickness is *political*.

Drawing on these histories, “sick” as it is used today within disability communities, is a reclamation of a term historically used against us. Similar to the reclamation of “crip” (as in crippled), the use of the term “sick” is a claim to our own identity that, as Leroy Moore (2014) states, flips “what the mainstream has thought of as negative, gross, and ugly into political and personal pride and acceptance” (26). It elicits disgust and draws on how it has been used to demonize chronic, physical, cognitive, and mental illnesses throughout history. Moreover, “sick and disabled” is often a way for us to identify other members of our community and it employs a cross-disability solidarity, a core tenet of Disability Justice that is

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. (Berne 2015)

“Sick and disabled” includes both apparent and illegible (often called “invisible”) disabilities. Some of us are diagnosed, some not. Some of us use wheelchairs, canes, masks, braces, slings, oxygen tanks, feeding tubes, walkers, hats, or colostomy bags, and some of us may seem able-bodied or able-minded. Disabled communities are linked together by our identity and experiences of oppression and discrimination, but that in no way implies that we are all the same. Within this terminology, I include sick and disabled people who may not have medical diagnoses or may be self-diagnosed, as many systems of medical care are contingent on measurable symptoms and insurance providers, as well as those who do and do not seek medical care. Throughout this paper, I center the terms “sick” and “sickness” but I also use “disability,” “illness,” and “pain” to draw upon the complexity of language that encompasses sick and disabled identities, while also noting that not all people with disabilities identify as sick, not all sick people identify as disabled, and not all people with chronic illness or disabilities identify with either of those terms.

In relation to archives, sickness has been addressed as both subject and metaphor⁶ often to illustrate the power of archives. Michel Foucault, frequently engaging with the historical medicalization

and categorization of sick, disabled and mad bodyminds, defines classificatory specification as “system according to which the different ‘kinds of madness’ are divided, contracted, related, regrouped, classified, derived from one another as objects of psychiatric discourse” (1982, 42).⁷ Most notably, Jacques Derrida (1995) coined the term “archive fever” which centers feverish — sick — archival manifestations of power.⁸ Taking up Derrida’s *Archive Fever*, Carolyn Steedman (2002) focuses on how archives can be sick-making: the physical flotsam of an archives — dead skin cells, hair, fibers, fungi or preservation chemicals like anthrax — is the source of physical and metaphorical infection, dispersion, and accumulation of history. Archives and the dust they hold are remnants of human experience that can make us sick physically, by breathing in airborne pollutants, or metaphorically, by forming histories and social memory activated by archival users. These works demonstrate the politics of sickness in archives. First, how archives delineate, replicate, and embody the fear, medicalization, and interinformed systems of oppression. Second, they show how archival work can be inaccessible — because of preservation chemicals, repetitive physical work, inaccessible reading rooms, as well as academic elitism — to the sick and disabled communities who are affected most by their creation, organization, and documentation.

Methodological Foundations

Looking at the Field Museum’s records of Tillet, made hyper-legible through Field’s documentation, I am well aware of the proliferation of absences in his narrative. In 1940, Field brought Tillet to pose with a caveman display at The Field Museum for a photoshoot, framing him as the “missing link.” I sat with these records for hours, sifting through many newspaper and magazine clippings featuring images of Tillet posing with the cavemen in the diorama, sometimes mimicking their stances, other times interacting with the mannequins by raising a club and joining in on the drama of the constructed scene. In a book written about Field’s anthropological travails, Field (1967) reflects,

The champion’s [Tillet’s] excellent sense of humor was a little tired when he found himself, wearing a reindeer skin and gripping a prehistoric stone ax, standing motionless within the Neanderthal family group.... I directed his sudden coming to life and plunging forward out of the group with a wide-open yell while brandishing his mighty ax. (230-31)

These records — the photos, newspaper articles, and Field’s reflection — allow for a partial glimpse into Tillet’s life at that time, and I’m grateful to witness this sliver of his frustrations, enjoyment, and experiences. Yet these records also lack Tillet’s voice and underscore a common issue in witnessing records about disability.

Responding to these records, I first turn to critical disability studies, which allows for the identification of the systems of devaluation that produce records such as these and the absences within them. Building on this, I turn to archival studies to expand upon the systems that not only produce records but those that function within archives. These two methodologies lay the foundation for building a critical disability archival methodology, which facilitates identifying the multifaceted ways that absences and partialities get produced and sustained.

Critical disability studies approaches have formed a crucial methodology for addressing the systems that document, control, and interact with disabled people. Kim (2017) articulates a “[c]ritical 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

decenter whiteness *and* able-bodiedness/mindedness. With a critical lens, disability studies scholars have used archives to tell some of our histories; records can serve as evidence to tell crucial pieces of disability history while also having omissions (Rembis, Kudlick, and Nielsen 2018). Rosemarie Garland-Thomson (1996), for one, uses records to trace the history of the public display of disabled people that were also racialized, sexualized, and gendered through analyzing archival material.⁹ She traces how Julia Pastrana, an Indigenous Mexican woman often billed as “The Ugliest Woman in the World,” was documented throughout her life. Records — such as Pastrana’s marriage certificate to her manager that ensured his profit, medical journals that documented and debated her physical differences, and the advertisements for her (living and posthumous) exhibitions that produced a profit — allow for many disability scholars, like Garland-Thomson, to re/tell history and to bring the violent aspects of disability history to light (e.g., Burch and Rembis 2014; Hamraie 2017; Pickens 2019; Rembis, Kudlick, and Nielsen 2018; Schweik 2010).

A critical disability methodological lens allows me to articulate how the records that document Tillet echo the common ways in which disabled people are represented in records. The creation of records by and in service of those in power demonstrates how social, cultural, and ideological systems around disability, race, masculinity, and also evolution and colonial thought produce partial insights into Tillet’s life. The photographs of Tillet with the museum’s caveman display are nestled among pages of accompanying material in the scrapbook: photographs of Tillet having his head and hands measured for cranial pseudoscience under an anthropological lens (Time Inc 1940, 67-8); x-rays of Tillet’s skull comparing measurements and thicknesses to that of “Normal man;” and a full-page illustration of Tillet’s head and body is placed in sharp contrast with two identical illustrations —one of “Neanderthal man” and “Modern man”— effectively framing him as the “missing link.”¹⁰ Focusing on these records’ connections to systems of knowledge production, a critical disability methodology centers how the records that represent disabled people can be an extension of “systems that seek to delimit, contain, and exploit” (Kim 2017). These documents emphasize Tillet’s disability as a medical “anomaly,” which obscures his perspectives on his identity. They serve as evidence of evolutionary hierarchies, engendering ableist perspectives into the records. These records therefore can function as evidence of an *entanglement of systems* which produce(d) hierarchies that devalue disabled people, people of color, and Indigenous people, such as phrenology, anthropology, and medicine. And such systems are embedded in racialized, colonial hierarchies invested in the delineation of difference which silence the voices of records’ subjects (Meekosha 2011). Accordingly, these records embody the perspectives of Field and others who profited from analyzing Tillet, imbuing their social, cultural, and ideological attitudes within them.

In developing a critical disability *archival* methodology, I want to underscore how those multiple systems have produced records about disabled people, but I also want to emphasize the granular ways in which values and omissions are also created and embodied within archives and their processes. Archival studies — a field dedicated to studying the ways in which archives and archivists shape (and have shaped) the ways in which history is understood — has developed an archival methodology “to establish, maintain and analyse the formal quality of process-bound information. It is used to bring about, assess and maintain the bond between the records and the generating work processes” (Thomassen 2001, 383). Archival studies approaches assess the granular ways in which values are ingrained in archives, not only through the creation of records, but their accumulation, appraisal, description, and access within physical repositories (Caswell 2016). Michelle Caswell (2014) identifies these levels, “[n]ot 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” (10). Moreover, much work in archival studies places focus on how archivists are active participants in what narratives are preserved; they can inevitably only capture partial perspectives,

and, “[t]hrough the ways in which they organize information, archives create what is knowable and unknowable about a given historical moment and a group of people” (Koh 2012).

Through an archival studies lens, the absences in Tillet’s narrative are produced not only through the creation of records, but also through the decisions that are made in archives thereafter in how records are selected and accessioned into an archives (or not), organized and described by archivists, and therefore made accessible or inaccessible to researchers like myself, who encounter disabled people in history intentionally, accidentally, or unknowingly. An attention to the constellation of systems that produced these documents alongside the archival decisions made to keep, organize, and describe them allows me to think about: why were these documents selected to keep in the museum’s archives? How does the organization and description of these records maintain the authority (and coloniality) of their original purposes, as they are part of Henry Field’s personal papers? How do these archival decisions impact who can find these records? The systems that classify, document, and affect sick and disabled people, such as archives, libraries, museums, and other classification and ontological systems (Adler 2017) are bound up with carceral, colonial, medical, and cultural systems and imbue a variety of absences throughout archives and archivists’ decisions. Tillet’s records, like so many that document people with disabilities, were not described or labeled as depicting a disabled person — I hadn’t been able to locate these records through database keyword searches. It was only through a conversation with an archivist that I was able to witness Tillet, a legible example of a disabled person in history. This experience demonstrates how archival description, or the lack thereof, can frame how disability is understood, located, and (potentially) complicated. I’m drawn to think about how Field described and arranged these documents within a scrapbook, and subsequently, the decisions made in the archives to maintain these documents in the order which Field had arranged them and in the ways in which he described them.

Pairing an archival methodology with a critical disability studies methodology, as I’ve shown, emphasizes the granularity of systems that not only created records that so violently document(ed) people with disabilities, but also those that treat(ed), shape(d), and impact(ed) the access of records through the archives that hold them. A *critical disability archival methodology*, then, not only allows me to think about the systems of devaluation that produce certain types of records, but also how those values become embedded in archives. These two fields can coalesce to demonstrate the complexities of absences (and therefore interpretations) within archival material. To expand critical disability studies methodologies to archival work and research is to consider what is in or absent from the historical record and also the multiple layers of past and ongoing decision-making that imbues additional absences into the narratives of our past. This methodology allows me to consider the decisions made to create these records, to keep them in an archives with the Field papers, and to not describe or label them as being about a person with disabilities — decisions which further proliferate absences. Just as a critical disability 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 and what we can know. Highlighting archival decision-making does not necessarily deem the choices made around Tillet’s records as “right” or “wrong,”¹¹ but instead *draws attention to* the fact that decisions were made, although they may merely replicate past language. This methodology helps in making absences and the systems that produce them palpable through a complex understanding around archival erasure and the surviving documentation of disability.

Therefore, in developing a critical disability archival methodology, I consider not only the partiality of these records, but also all of the disabled people who may not be legible in documents because of ableist processes of documentation, categorization, and archival decision-making. For example, I think about the other records that are not identified as documenting disabled people; records of people who

may not appear sick or disabled in legible ways; disabled people who subvert systems and avoid documentation; records that were never made about disabled people; and records that were not deemed worthy to be kept in an archives, all of which impact our access to these narratives. Particularly, this methodology facilitates in highlighting the disabled people of color — in contrast to Tillet, a white disabled man — whose records I have yet to locate, that are erased from this history.

Reading Records through Sickness: Teasing Out the Unknowable and Fluctuating

After teasing out the processes through which absences are imbued in records, I now want to expand a critical disability archival methodology by turning to themes in the writings of sick and disabled people. In other words, the absences in Tillet’s archive have been shaped by people in power, systems of documentation, and archival processes. How can we now grapple with the ways in which his bodymind and experiences are unknowable to us as well as with all of the ways that other sick and disabled people might not be legible in records?

As part of a critical disability methodology, Minich (2016) “emphasize[s] that this scrutiny of normative ideologies should occur not for its own sake but with the goal of producing knowledge in support of justice for people with stigmatized bodies and minds”. This methodology recenters coalition building, social justice work, and the embodied experiences of sick and disabled people. Likewise, I argue that a critical disability archival methodology should problematize the systems through which records on disability are produced and maintained, while also remaining present with the nuanced, embodied ways in which sick and disabled people experience daily life. This section therefore turns to sick and disabled people in order to theorize the ways in which our experiences can’t fully be known. I heavily rely on their words to tease out common threads among our experiences.¹² So in building this methodology, I am also practicing it — thinking in solidarity with sick and disabled people and resisting summarizing our experiences neatly, I instead articulate the complexity and nuances of our lives. In developing a critical archival disability methodology, conceptualizing sickness centers the layers of unknowability within our experiences. It encourages one to question: What may not be legible? What’s worth the energy it takes to explain? And ultimately what may be simply unexplainable?

Sickness as Unknowable

For those of us with chronic illnesses, disability and sickness may have varying degrees of legibility. Many people in the sick and disabled communities are continually advocating not only to be recognized by the state (to obtain medical care, assistive devices, and social support) but also on a daily basis by those around them, as often illnesses, disabilities, or pain are not visibly apparent. I’m often recognized as sick because I walk with a cane (although it’s comical how many people ask me if it is “just an accessory”), and I look even sicker when I wear my portable oxygen tank. But without these, if someone doesn’t know how to read other, more subtle, signs of my sickness or my disabilities, I may not always appear as sick. Peggy Munson (2000), writing about Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), states: “One thing is certainly deceptive: CFIDS patients rarely look as sick as they are” (4). She continues, “Illnesses are rarely legitimated unless they result in death or severe disfigurement. Until those consequences are actually seen and felt, a mythology follows the ill in their travails” (10). And Nitika Raj (2014) writes, “My struggle with invisible illness and chronic pain is this - invisibility” (117). Consequently, as Susan Wendell (2001) articulates, “People who are chronically ill with these diseases are likely to have trouble getting recognition of their illnesses-if not by the medical profession, then by

friends, relatives, acquaintances, employers, insurers, and others who believe that they should have recovered from their diseases long ago” (20). As many aspects of sickness aren’t initially apparent, outsiders can sometimes have difficulty recognizing the experiences of those with less legible disabilities. Many of us are all too familiar with being told “you don’t look sick,” as if we need to have a legible aspect of our disability or illness in order for it to be taken seriously. Moreover, people are more likely to see those of us who are chronically ill on “good days,” where the days spent in bed, sick, in pain, and healing may go unnoticed or unaccounted for.

As sickness, pain and disability may not be legible to those who lack context, assume able-bodiedness/able-mindedness, or simply aren’t entitled to know about someone’s personal experience, many disabled and chronically ill people think critically about how to externalize their experiences. Hedva (2016), contending with how sick and disabled bodyminds can be excluded from the very activism that seeks to liberate them, writes “for those who are faced with their vulnerability and unbearable fragility, every day, and so have to fight for their experience to be not only honored, but *first made visible*” (emphasis mine). Raj writes, “The tensions I live come from not appearing sick, but then trying to describe an inner, debilitating experience to people in daily life - coworkers, roommates, friends, partners, family, community members. And feeling that I have to talk about myself in a disempowering way to be validated — because it’s about verbalizing pain and depression and ER visits” (2014). These words demonstrate that not only do experiences of pain and sickness sometimes require us to reach for the most conventionally serious (read: medically legible) vocabularies to register the weight of our experiences to others, but also people often have preconceived notions of what pain, illness and disability *should* look like. Ben G. (2014) states that “[t]he contents of those experiences [commonly conveyed about schizophrenia] are generally perceived as being so different, so horrific, that when compared to the experience of a so-called normal person, I sometimes feel like I might as well have been born a creature as strange and alien as a bat” (222). The experience of sickness, disability, pain, and illness may not be believed, particularly with women of color, where verbally communicating internal experiences may be doubted without physical “evidence.” To communicate the personal experience of being sick, ill, disabled, or in pain is complex. So, if we rely on what is readily apparent — with people and in records — we miss a lot of the sick and disabled experience.

Chronic illness, pain, psych, and cognitive disabilities can go underrecognized, but they may also not be legible because of the ways in which disabled people have learned to navigate the world. Garland-Thomson (1996), reflecting how disabled people use tactics such as performing charm, humor, or deference in order to manage relationships and “to relieve nondisabled people of their discomfort,” warns that if “disabled people pursue normalization too much, they risk denying limitations and pain for the comfort of others and may edge into the self-betrayal associated with ‘passing’” (13). Garland-Thomson points to the tension between articulating pain, sickness, or disability and what may not be worth the energy it takes to explain. Amy Berkowitz (2015) expands this notion by stating, “[e]ven on regular paper, writing makes my hand cramp up like a claw... No notebook goes unpunished. It’s always a question of: what’s worth writing down?” (122). Berkowitz illustrates not only the difficulty of communicating internal experiences, as it takes an incredible amount of emotional (and physical) labor to navigate language and relationships, but also there is a constant weighing of what is worth the energy it takes to externalize. Moreover, as Cheryl Green (2014) articulates through her experiences with brain injury, “We come to internalize the belief that no one on the outside can relate” (2014, 71). G. (2014) echoes that “[t]he goal is to open the door and let madness enter the world, though always keeping in mind that you can only remain at the threshold” (223). Sickness helps conceptualize the ways that illness and pain are difficult to communicate to those who do not experience it and also how many aspects of sickness are illegible. Acknowledging the limits of communication by thinking through the ways in which sickness may be

indescribable or just *undescribed* — experienced differently by everyone — helps lay a foundation for coming to terms with the unknowability of archives and the records they hold. To build a critical disability archival methodology emphasizes centering the multiple ways in which sickness and disability can be illegible in records.

To reiterate, reading the records about Tillet tells one side of disability history: understanding that these records were created by and for those in power allows us to contemplate how the creation of records and archival interventions (or lack thereof) reifies the spectacularization of disabled bodyminds and reflects ideologies of ableism, colonialism, and white supremacy as well as the absences produced through such systems. Yet, a failure to go beyond the interpretation and assumption of Tillet's lack of agency and exploitation might also do him a disservice. By expanding a critical disability archival methodology through the words of sick and disabled people, I can also understand these records as evidence of the complex nature of absences. Kim (2017) writes, “[r]ather than reading for *evidence* of self-ownership or resistance, then, [crip-of-color critique as a critical disability methodology] reads for relations of social, material, and prosthetic support — that is, the various means through which lives are enriched, enabled, and made possible” (emphasis mine). By reframing evidence around concepts of complex unknowability or legibility, I am drawn to think about all that is not there: I do not know if Tillet identified as sick or disabled, and there’s so much that is unknown about him. Conceptualizing sickness offers an approach that relies less on traditional forms of evidence, and more on the layers of unknowability, beyond what is legible in the records of his bodymind.¹³ Although I first think about the inevitable absences and omissions in the creation of these records and the multiple systems that instill absences into records, I also can consider the *intentional* absences of sickness — how sick and disabled people have learned to navigate the world and choose to translate or externalize their experiences. By thinking about the unknowability of sickness — what is legible, what can be communicated, and what he may not have wanted to communicate — I can see the limits of these records and recognize the complexity in those absences. *Archival absences are not only produced by those in power, but are also inherent to the lived experience of being sick or disabled.*

Sickness as Fluctuating

Additionally, conceptualizing sickness allows me to think about the lack of fixity of sick and disabled experiences and how a critical disability archival methodology can complicate archival research and interventions. Much disability studies literature has highlighted the relationality of illness, sickness, and disability. By centering how architectural barriers and discriminatory attitudes produce disability, the social model of disability, for one, has been used to demonstrate how disability changes through different spaces and interactions, creating sites for political change (Shakespeare 2006). Expansions of the social model have shown how sickness and disability are also formed in relation to resources, materiality, values, and power (Brilmyer 2018; Carey 2010; Hamraie 2018; Kafer 2013). What is more, the embodied experiences of sick and disabled people also show how sickness not only changes through inaccessible spaces or ableist attitudes but also shifts day-to-day, minute-to-minute, even without social or architectural barriers or environmental factors. Wendell (2001), for example, writes, “[s]ome diseases, such as MS and rheumatoid arthritis, can behave like recurring acute illnesses, with periods of extreme debility and periods of normal (or nearly normal) health, or they can have virtually constant symptoms (such as fatigue or pain)” (20). People with chronic fatigue, moreover, can have symptoms that are contingent on how much they have exerted themselves or what other symptoms are present at a given moment. Furthermore, as we age, our bodies experience illness, disability and changes in mobility in different ways (Kafer 2013, 25-6). Conceiving of disability (or debility) as a part of our lives¹⁴ begins to

address the changing nature of bodyminds, as, “What we understand as impairing conditions — socially, physically, mentally, or otherwise — shifts across time and place” (Kafer 2013, 7) which “demand[s] an unsettling of [disability’s] certainties, of the fixed identities of which it is bound up” (Price and Shildrick 2008, 243). In other words, sickness, illness, and disability are never a stagnant aspect of one’s bodymind, or identity.

Embracing the fluidity of sick and disabled experiences, a critical disability archival methodology correspondingly illuminates how records only capture pieces of disability, highlighting how these moments are spatially, temporally, and materially contingent. The records about Tillet are only ever incomplete; they provide glimpses, all of which are mediated through Field’s words and the archival decisions made about them. This is only a partial perspective, a few moments, of what I can assume was Tillet’s complex relationship with Field, the museum, and medical personnel. I am drawn to think about other days in his private life and in his career as a boxer, where he could experience a multiplicity of pain, happiness, or resistance. What conceptualizing sickness gives us is a way to think through the complex lived experience of disability — contingent on different bodies, time, space, and interactions — which can impact how we interpret records expansively.

Just as sickness and disability are temporally, spatially, and socially contingent, so too do archives and archival material shift. Not only do the fluctuating experiences of sickness allow for us to understand the continual changing nature of disability, but also this lens demonstrates how archives and our interpretations of them are also temporally situated, resisting the stagnation of our analyses. As an archival user, I read these records through a contemporary disability studies lens, through my past experiences of research, ableism, and knowledge of Disability Justice. These records will continue changing through others’ interpretations, across individuals, places and times.

Centering how sickness and disability are continually fluctuating also challenges a stagnant rehabilitative approach to archival material. *To center the complexity of sick and disabled bodyminds is to also unsettle our responses to them.* If disability is thought of as a stagnant “problem” of the bodymind, as it is framed through the medical model of disability, then rehabilitation is not only an assumed response (to eliminate disability or sickness) but also is a one-dimensional, universalized approach to normalizing or “fixing” disabled bodyminds (Linton 1998, 11).¹⁵ And if the “problem” with disability is reduced to only built environments, solutions can also lean towards a rehabilitative notion of “fixing” an issue: the design practice of barrier-free design, for example, aligned more with rehabilitation models of disability, where if the elimination of physical barriers equate the “elimination” of disability (Hamraie 2017, 101). Katie Finning (2017) writes about the fluctuation of chronic illness: “My health always goes in waves – bad patch, good patch, bad patch, good patch. But the length and severity of the bad patches, and the length and goodness of the good patches, varies massively.” Depending on how she feels, she adjusts her schedule, the amount of activities, and embraces that every day is different. If we understand the experience of disability and sickness as changing in relation to social and built environments, discriminatory attitudes, materials, and power inequalities, as well as differing across individuals, time and place, then bodyminds are considered to be always in flux and there is not a single or final solution, but instead an acceptance of fluidity and mutability. This stance acknowledges how sickness fluctuates, which makes space for different solutions, whether that’s empathy, medical intervention, spatial reconfiguration, assistive technology, and thus political, cultural, and material change.

Embracing sickness, in its complexity and multiplicity, therefore can add to a critical disability archival methodology by challenging neoliberal reductive conceptions of rehabilitation and the finality of fixing, which can be applied not only to archival research but also to archival praxis. Archival scholars and practitioners often advocate for the inclusion of communities in the processing of archival material that represents them, encouraging “archivists to (re)search thoroughly for the missing voices, for the

complexity of the human or organizational functional activities under study during appraisal, description, or outreach activities, so that archives can acquire and reflect multiple voices, and not, by default, only the voices of the powerful” (Schwartz and Cook 2002, 17). Sara White (2012), for example, stresses the need for archivists to work closely with disabled donors during archival appraisal, arrangement, and description processes to grasp a more nuanced understanding of collections (124). However, although the involvement of disabled people in processing their donated collections can add a crucial perspective to materials, there are vast amounts of records on people with disabilities where the subjects are no longer living. While having first-person witnesses to the collection’s subjects can provide insight, in other circumstances it may be difficult to involve *living* communities that can speak to some aspects of *past* disabled experiences. Moreover, as Elisabeth Kaplan (2000) has made note of, although the inclusion of communities within archival processes is an invaluable practice, it may suggest a finality in solving the “problem” of representation. Kaplan points out “a conviction [in archival practice] that somewhere out there exists an authenticity to be restored to the archival record, a natural balance to be righted, a bias to be erased and a ‘real’ identity to be documented” (146). These arguments point to a potential slippage in archival work towards a finite understanding of the “right thing” and of “empowerment” of archival subjects. How, then, do archivists contend with not being able to achieve these desired goals (or only achieve them in part) around records that represent the history of disability?

Berkowitz (2015), pointing to the complexity of chronic pain illustrates that “[w]hile a puzzle can be solved with just one or two missing pieces, pain is much more complicated, and talking about pain—especially chronic pain—as if it has an easy answer can be irresponsibly deceptive” (14). Nonetheless, Anna Leahy (2018) tells us “[g]aining a deeper understanding of one’s own pain or someone else’s has the potential to radically alter our interactions day to day, and to shift our focus away from a desperate need to be fixed and also from the exhausting performance of wellness into a more manageable way of living a fully realized life.” Yet, as Kim (2017) states, a critical disability methodology, “prompt[s] us to move away from reform-oriented strategies that prioritize the attainment of legal rights, and toward more disruptive modes of organizing life altogether—radical imaginaries modeled, for instance, in the writings of disabled poet-activists Audre Lorde and Gloria Anzaldúa”.¹⁶ Sickness helps disrupt the pitfalls of solutionism in archival practice — a shift away from a simplified, universalized (medical model) approach and towards more radical, creative, and ongoing relationships with archival material and the inevitability of partiality in archives.

The inclusion of disabled communities in archival processes is a vital move towards complicating archival narratives. As sickness and disability differ across individuals, so too might individual community members have differing opinions of how to process archival materials, which can work towards providing multiple interpretations of records. However, the inclusion of disabled people as an archival goal could risk becoming a box to be checked, a solution to be reached. Through an expanded methodology around the fluctuation of sickness and our responses to it, both towards the representation of subjects of records and our reactions to them, fixing records is not only impossible, due to cultural and temporal shifts, but also an unrealistic misorientation to change and addressing absences or limits. Thinking through the multiplicity of sick identities and experiences, reconciling a record is an ongoing process. *A critical disability archival methodology thinks through and past the rehabilitation of archival records, towards their infinite possibilities and encourages a constant engagement with communities, records, and plurality.* Acknowledging that not all records need the same thing, will never be complete, and are in and of themselves constantly changing, and contingent may further resist a stagnant idea of “fixing,” correcting or filling in all the gaps.

Conclusion

While archival research provides us with a piece of disability history, critical disability studies' intersectional methodological lens complicates the ways in which we understand systemic absences, partialities, and omissions. 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. Yet, there is also so much more that is missing from the records. Given such narratives' preservation in archives coupled with the lack of archival interventions, records have the potential to maintain harmful rhetorics that continue to impact disabled people's lives. Therefore, a critical disability archival methodology, as I have shown, complicates the absences within records and provides a methodology for both people using archives as well as archivists to work in solidarity with sick and disabled communities.

This methodology does not provide a concrete solution to archival absences, but as a methodology committed to working with the communities which we research (in disability studies and more recently in archival studies), it frames research paradigms, practices, and techniques with the complexity of disabled experiences. As I have demonstrated in the case of Tillet, applying it brings an awareness to the complexities of absences that occur when attempting to understand disability in the historical record. Especially when “disabled bodies are disavowed, shut away from the mainstream, locked into bedrooms” (Kuppers 2013, 44) and are excluded from activist spaces that can be in solidarity with their very liberation (Hedva 2016), a critical disability archival methodology can gesture toward complicating the multiple ways in which disabled people are absent from records.

First, by combining critical disability studies as a methodology with archival methodologies, attention is drawn to systems as well as to how archives proliferate absences and omissions. This focus highlights how disability is intertwined with systems of power and how archives reflect, maintain or intervene in the values and ontologies of other systems. A critical disability archival methodology encourages nuanced understandings of both what is present and absent in records and the decision-making that produced and maintain them in archives today. Second, reconciling the unknowability both of records, as well as the communities represented within them, facilitates a methodological shift away from assuming that someone's experience can be fully understood and therefore represented. As sickness demonstrates, there can be a limit on what can be shared and thus legible in historical records. Understanding the complexity of absences within sickness provides a critical disability archival methodology with a way to complement reading along the archival grain (Stoler 2010), against the grain (Chaudhuri, Katz, and Perry 2010; Hartman 1997) and/or along the biased grain (Fuentes 2016) in order to critically address absences in records. Lastly, through centering the ways in which sickness and disability fluctuate — over time, place and interactions, as well as across individuals — this methodology further acknowledges the partiality of archival absences as well as resists some of the solutionism of archival interventions to combat the unknowability of historical records. Although involving disabled people in archival processes and decision making can complicate some narratives, recognizing their inevitable partiality is a crucial aspect of archival work. A critical disability archival methodology, then, is less about providing solutions to archival processes and more about making space for continual creative and radical interventions, while also recognizing “the difficulty in determining who is included in the term ‘disabled,’ refusing any assumption that it refers to a discrete group of particular people with certain essential qualities” (Kafer 2013, 10). To work in solidarity with sick and disabled people is to know the complexities that limit what we *can* know, and then, in response, to disrupt simplistic responses to them. Using this methodology, researchers and archivists alike may develop an investment in the complexity of

archival absences and the nuance with which they need addressed. As much of historical research within critical disability studies and archival studies involves scrutinizing records in attempts to understand pieces of the past, this methodology is a way of complicating what is in records, what might not be there, and what could be.

This framework feels like just the beginning of what could be a plethora of responses to archival absences. Perhaps this framework could complicate what we ‘believe’ in records, by centering how the sickness and pain of women, particularly women of color, is often doubted and their illnesses are not legitimated (Danquah 1998; Moraga 2015; Mollow 2006; Pryma 2017). Moreover, I’m interested in how, in archives and records, we could further serve those who do not explicitly identify as sick and disabled and how this lens might expand archival conversations to center ableism and disability while looking at records that aren’t explicitly “about” disability. An expansion to centering systems that devalue certain bodyminds could draw attention to records that are not necessarily “about” disability, but, instead, to how ableism, as Douglas Baynton (2001) outlines, was used to justify the enslavement of Black people, or, as Adria Imada (2017) writes, how those who were colonized are always already figured as disabled.

As access is central to the project of critical disability studies, I wonder what contending with absences might mean for access to records and archival spaces. With this lens, archival accessibility could be similarly problematized — as access to our histories is equally important as contending with our representation in materials. I wonder what archival interventions this methodology might make room for: more radical and expansive descriptive practices for the location of our own narratives; new configurations for archives reading rooms; and the elevation of those most impacted by ableist, racist, and classist norms produced both in academia and archival spaces to address archival inaccuracies. Lastly, thinking about sickness, illness, disability, and pain could make room for the pain felt when working in archives: the pain of seeing disabled people represented in harmful ways as well as the pain felt when confronted with our absences, when we cannot locate ourselves in history at all and bearing witness to the violence of the past, which I feel in my bodymind today.

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Endnotes

1. I intentionally vacillate between identity first and person first language when talking about disability in order to reflect the complexity of how people identify within these communities as well as the nuances of researching disability in history, where people might have different relationships with disability.

2. Michelle Caswell Marika Cifor, and Mario H. Ramirez (2016) describe this archival erasure of identity in mainstream archives using 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, underrepresented or misrepresented in public records. Building off of this work, I also recently illuminated how disabled people feel an inherent sense of violence in witnessing disabled people in records, while they also deeply relate to them (2020).

3. 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.

4. I use “us” and “we” throughout this text to engage with a broad group of people — namely as a Disabled and chronically ill person, to refer to disability communities, as well as an archival studies scholar to highlight a call for archivists to engage with disability in history, and lastly, to point outward as to not limit engagements with archives and records to those participating in traditional methods of scholarship, but to disabled and abled people both in and outside of academia.

5. As I am invested in investigating the textures of physical repositories, I use Caswell's (2016b) distinction between “an archives,” that is, an “actually existing archives” used in the field of archival studies and by archivists, from “The Archive” discussed more in humanities literature (2016b).

6. 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 depict seemingly negative aspects of archives. Especially in a paper that is drawing out concepts from sick and disabled experiences, I am wary about producing a similar slippage into metaphor. Susan Sontag (2001) 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). Likewise, Sami Schalk (2017) critiques the use of disability as a metaphor for loss or evil as it “fails to read representations of disability as anything other than metaphoric” (140). 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” (148). 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. Instead, I want to draw on the complexity of sickness — positive, negative, ambivalent, and messy — and not use it metaphorically, but concretely. This work does not aim to use sickness as a metaphor, but instead to ground critique and exploration in embodied experience of sickness, pain, illness and disability, as they are acute examples of the unknowable.

7. 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* (Foucault 1994) and *History of Madness* (Foucault 2013) — but also, more loosely, to draw on the affective nature of archives and memory — such as with *The Archaeology of Knowledge* (Foucault 1982), *The History of Sexuality*, (Foucault 1990) and *The Order of Things* (Foucault 1994).

8. Derrida (1995) draws not only on the institutional power, stemming from archives and their records, but also on language and experiences that draw on the politics of sickness. His language of prosthesis, the embracing of compulsive, repetitive behavior, and the project of “civilizing” all excavate the history of sick, disabled, racialized, and classed bodyminds through metaphorical use of sickness. These metaphorical uses continue today: for example Andrew Lison et al. (2019) use “schizophrenia” as an interpretive framework for archives, which Brian Watson (2020) critiques as “offensive and reductionist.”

9. Much of Garland-Thomson's visual material comes from archives within institutions such as the Circus World Museum, Shelburne Museum, Somers Historical Society, Harvard Theatre Collection, and the Library of the College of Physicians of Philadelphia.

10. The tryptic states, “The Angel has a body much like that of the historic Neanderthal man, with strong, sloping shoulders and barrel chest. His face, which was formerly perfectly normal, now has the hammer-jaw and big nose characteristic of acromegaly.” Whereas the “Modern man's” “whole build is slimmer and more delicate than that of his far-distant ancestor.”

11. I acknowledge how archivists have to work within budgetary and time limitations to process collections, so inevitably decisions are made on how to describe, organize, and maintain records.

12. While this section might *seem* like a long literature review, I intentionally rely on the words of sick and disabled people to emphasize the nuances among us and theorize these threads.

13. Parallel to what Hartman (2008) terms “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” (12).

14. Kim Sauder (2015) critiques the use of “Temporarily Able-Bodied” or TAB as ability is not always temporary, and seeing it as inevitable can further stigmatize and promote disability as something to be feared. Alison Kafer (2013) notes, “[s]eeing disability as political, and therefore contested and contestable, entails departing from the social model’s assumption that ‘disabled’ and ‘non-disabled’ are discrete, self-evident categories, choosing instead to explore the creation of such categories and the moments in which they fail to hold” (10). Wendell (1996), also highlighting the lack of a binary, questions the limits of how far someone needs to not be able to walk to be considered “disabled.”

15. I do not argue against medical interventions for sick and disabled people, but I wish to challenge that as the de facto response that leaves out the complexity of disabled experiences.

16. Along these lines, Caswell (2016) highlights as feminist ethics in archival practice.

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