

CLAIMING DISABILITY IN APPALACHIA

A Thesis
by
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Abstract

CLAIMING DISABILITY IN APPALACHIA

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Appalachia has been seen as a disabled region, commonly positioned as needing development or remediation to be brought in line with the rest of the United States. Instead of automatically assuming that this disablement is a bad thing, I interrogate the multiple meanings and potentialities of disability. I draw on the work of disability scholars and activists to discuss the ways that disability can be a transformative site for social justice. Taking a critical disability studies methodology, I track the ways in which Appalachia has been disabled, primarily through histories of environmental extraction and domination by outside forces. Perceptions of Appalachia as a disabled region, along with the lived experiences of disability and impairment, are salient to Appalachia's past, present, and future. I consider how disability relates to and can inform social movements in Appalachia, including labor, environmental justice, LGBTQ+ organizing, and caregiving. Throughout diverse case studies that challenge the boundaries of what we consider disability, I argue that an understanding of disability is crucial to the question: *What would a good future for Appalachia look like?* Instead of assuming that this hypothetical good future would include

an eradication of disability, I contend that disability offers a valuable source of cultural knowledge and expertise, especially for cross-movement building in times of precarity.

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Dedication

To all the disability justice advocates who help imagine a better world for us all.

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Introduction

Appalachia has been discursively constructed as disabled, with early writing casting its inhabitants as both physically and mentally deviant. For example, it was posited that the first European settlers in Appalachia were criminally inclined Anglo-Saxons¹ and that the isolated landscape led to intermarriage,² thus leading to a prevalence of negative genetic traits that have persisted in the Appalachian population. Appalachian people were, and still are, cast as physically different, and often culturally deficient, in need of uplift by missionaries, teachers, and public health officials.³ Through this process, Appalachia becomes a space set apart from the rest of the nation, with Appalachian “bodyminds”⁴ also understood as deviant. This othering has exacerbated economic and cultural marginalization of Appalachia, as well as the perceived and actual experience of disability.

This perceived deficiency justifies attempts to “develop” the region, often through practices of natural resource extraction that have, in many cases, increased rates of disability through associated health problems.⁵ For instance, occupational injuries were common

¹ Harry M. Caudill, *Night Comes to the Cumberlands: A Biography of a Depressed Area* (Boston, MA: Little, Brown and Company, 1962).

² Jack E. Weller, *Yesterday's People: Life in Contemporary Appalachia* (Lexington: University of Kentucky Press, 1965).

³ Henry D. Shapiro, *Appalachia on Our Mind: The Southern Mountains and Mountaineers in the American Consciousness, 1870-1920* (Chapel Hill: University of North Carolina Press, 1978).

⁴ In using the term “bodyminds” I to resist a Cartesian dualism that posits a separation between the mind and body as a way to challenge normative knowledges of the body. See Margaret Price, “The Bodymind Problem and the Possibilities of Pain,” *Hypatia* 30 (2015); and Sami Schalk, *Bodyminds Reimagined: (Dis)ability, Race, and Gender in Black Women's Speculative Fiction* (Durham, NC: Duke University Press, 2018).

⁵ Brian T. McNeill, *Combating Mountaintop Removal: New Directions in the Fight against Big Coal* (Urbana: University of Illinois Press, 2011).

among those who worked in the logging industry, and so-called “black lung” is widespread across central Appalachia due to decades of coal mining and processing.

Today, inadequate healthcare, lower levels of educational attainment, and few employment opportunities all factor into Appalachia’s high rate of social security disability payments,⁶ with central Appalachia having a disability rate of 13.9% - among the highest in the nation.⁷ Appalachian people also experience some of the worse health outcomes in the U.S. People in Appalachia report 14% more days of feeling unhealthy, have a 17% higher rate of suicide, a 37% higher rate of poisoning mortalities, and have a noted shortage of health care providers in comparison to national averages.⁸ These examinations present disability primarily as a biomedical, public health problem in need of solving, rather than seeing disability as a complex sociocultural and political identity for persons living in and living through these conditions. While these health disparities do need to be addressed, disability is a far more complex and multifaceted way of being.

Disability is a contested and unstable category that may unify individuals into a community due to shared experiences of existing outside of the established norm and facing similar social challenges. Social groups have formed around disability across the globe.⁹

⁶John L. McCoy, Miles Davis, and Russell E. Hudson, “Geographic Patterns of Disability in the United States” *Social Security Bulletin* 57, no. 1 (1994); Kathy A. Ruffing, *Geographic Pattern of Disability Receipt Largely Reflects Economic and Demographic Factors* (Washington, D.C: Center on Budget and Policy Priorities, 2015).

⁷ Appalachian Regional Commission, *Creating a Culture of Health in Appalachia: Disparities and Bright Spots* (Chapel Hill, NC: The Cecil G. Sheps Center for Health Services Research, 2017).

⁸ Appalachian Regional Commission, *Creating a Culture of Health*.

⁹ E.g. Pamela Block, “Institutional Utopias, Eugenics, and Intellectual Disability in Brazil,” *History and Anthropology* 18, no. 2 (2007); Michele Ilana Friedner, *Valuing Deaf Worlds in Urban India*, (New Brunswick, NJ: Rutgers University Press, 2015); Karen Nakamura, *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan* (Ithaca, NY: Cornell University Press, 2013).

Such an affiliation is likely to be highly fluid, uneven due to lack of access to community, and fragmented among the lines of intersecting identities. Similar to Appalachia, disability is far from monolithic, and it would be naïve to suggest a singular experience of Appalachian disability. However, given the high rates of disability in Appalachia, as well as the neat fit of disability into national stereotypes of the region, it is plausible that there may be ways of experiencing disability that are filtered through layers of Appalachianness. These experiences of disability may not be unique to Appalachia but may be anchored in place-based experiences and regional stereotypes.

The title of this thesis reflects Simi Linton’s book, *Claiming Disability*, an early attempt to outline the field of disability studies. Linton writes: “The material that binds us [disabled people] is the art of finding one another, of identifying and naming disability in a world reluctant to discuss it, and of unearthing historically and culturally significant material that relates to our experience.”¹⁰ Drawing on disability as a politically charged sociocultural category, not just a medical or legal status, I “claim disability” throughout various social movements in Appalachia, situating disability within the region’s past and present and suggesting that it may have a role to play in Appalachian futures.

In Chapter 1, I examine the black lung movement as a previously unrecognized case study in disability rights. While most typically framed as part of labor history, I contend that black lung can be recontextualized as an example of disability organizing in Appalachia and an unrecognized part of the disability rights movement. Through Black Lung Association newsletters and other primary sources, I document the ways in which disability was salient to

¹⁰ Simi Linton, *Claiming Disability: Knowledge and Identity*, (New York: New York University Press, 1998), 5.

shaping a movement for occupational health benefits and suggest that there are precedents around community organizing around disability in Appalachia.

Chapter 2 continues this theme of extractive industry while taking a critical look at sustainability and environmental justice from a disability perspective. This chapter considers how environmentalism has failed to fully address the needs and experiences of disabled people, including those who were disabled by environmental harm. Instead of considering disability as an individualized problem, I argue that disability is something that circulates, trans-corporeally, between bodies and landscapes. Instead, I draw on queer ecologies and ecological disablement to challenge the nature/culture divide and show the relevancy of disability, beyond a condition to be eradicated, to environmental justice.

Building on queer theory, Chapter 3 considers the figure of the crip and how it might relate to the growing @QueerAppalachia movement. Using both Queer Appalachia and the Country Queers oral history project, I continue building on themes of disability and environmental queerness to relate the ways in which Appalachia has been presented as both fundamentally queer and disabled. I use this as a starting point to suggest cross-movement solidarity and ways in which disability justice might contribute to recognizing the intersections of queerness and disability, perhaps in the form of a “Crip Appalachia.”

Finally, Chapter 4 investigates disability justice through the idea of care networks. This chapter draws on ethnographic research conducted at my local senior center. Building on disability anthropology, I ask what sorts of local worlds are created around disability. In the space of a senior center, a site that promotes ideals of normative active aging, I instead focus on how participants rely on each other to create a space that allows for disability and

impairment. Taking the position that care is central to community building, I argue that disability justice can take place on small, localized scales.

Throughout this thesis, I purposefully employ a broad meaning of the word “disability” to refer to a range of both physical and mental impairments, along with the stigma of the presumption of such impairments. As Kasnitz and Shuttleworth rightly note, “Disability exists when people experience discrimination on the basis of perceived functional limitations. A disability may or may not be a handicap, or handicapping, dependent on management of societal discrimination and internalized oppression, particularly infantilization and paternalism, and on cultural and situational views of cause and cure and of fate and fault.”¹¹ Thus, one needs to question not only how disabled people experience their world, but also how historical forces have determined that the entire population of Appalachia has been constructed as less-than-able.

The cases throughout this thesis challenge the borders of what might be conventionally thought of as “disability.” In many cases, disability is most strongly associated with those who have a physical or sensory impairment. Yet, I argue that even though little critical attention has been given to the forms that disability takes in Appalachia, they are all the more valuable because they challenge definitions of disability to show how disability is understood in relation to sociocultural norms and political power. Disability Studies might be interpreted as making disability the object of study, but in this thesis, I follow Julie Avril Minich’s suggestion that disability studies is best utilized as a *methodology*

¹¹ Devva Kasnitz and Russell P. Shuttleworth. “Introduction: Disability Studies in Anthropology,” *Disability Studies Quarterly* 21, no. 3 (2001): 1-2.

– one that “proceeds not from narrowly-defined notions of what “counts” as a disability but one that seeks to radically disrupt the multiple sociopolitical ideologies that assign more value to some bodies and minds than to others.”¹²

Focusing on disability as methodology provides a way to examine disability without imposing a disability identity on those that I discuss. While I contend that there is value in claiming disability and thus a disabled identity, it would be overstepping to presume that everyone throughout my case studies feels the same way. Claiming an identity as disabled or as part of the disability community may be a path to empowerment for some,¹³ but for others, disability is associated with histories of shame and stigma.¹⁴ Tom Shakespeare discusses that disability identity can be formed through both a top-down and bottom-up approach,¹⁵ the former of which focuses on how disability and delineated by state institutions, a useful way of thinking about how Appalachia has been created as disabled. When in this thesis I refer to “disabled people,” I generally mean people who have been classified or positioned as disabled or disproportionately vulnerable to disability, generally through transnational capitalism and extractive industry.¹⁶ In this thesis, I primarily consider tracing disability’s

¹² Julie Avril Minich, “Enabling Whom? Critical Disability Studies Now,” *Lateral* 5, no. 1 (2016).

¹³ Margaret Wangui Murugami, “Disability and Identity,” *Disability Studies Quarterly* 29, no. 4 (2009).

¹⁴ Rob Spirko, “In Appalachia, Disability Stigma Has Dangerous Effects,” *Rooted in Rights*, September 21, 2018, <https://rootedinrights.org/in-appalachia-disability-stigma-has-dangerous-effects/>.

¹⁵ Tom Shakespeare, “Disability, Identity and Difference,” in *Exploring the Divide: Illness and Disability* eds. Colin Barnes and Geof Mercer, (Leeds: Disability Press, 1996).

¹⁶ I also acknowledge that language preferences for discussing disability vary in disability communities. While I feel that examining the ways people are actively “disabled” by society does important theoretical work, others would prefer “person first language” i.e. “person with a disability.”

creation as a social category as a method, without foreclosing the possibility of a firmer attachment to disability identity in strengthening future movements for social justice.¹⁷

This focus on method connects the academic work of disability studies with numerous activist movements that do not necessarily rely on disability identification. Minich provides “protests against racialized disparities in health, education, and policing; struggles for environmental justice and reproductive freedom; HIV/AIDS and fat activism” as examples of disability-related movements. In this thesis I add Appalachia, as a location of both real and discursive disability, to the sites of activist/academic collaboration, to ultimately ask: How is the category of disability implicated in what has been considered to be a “good future” for Appalachia?

The medical model of disability would suggest that a good future would not have disabled individuals. Instead, I follow Alison Kafer’s “political/relational” model, which suggests that disability is a “potential site for collective reimagining.”¹⁸ Instead of pathologizing individual ailments and impairments, I show how they have influenced the social landscape and created space for activist responses. Kafer argues: “Rather than assume that a ‘good’ future naturally and obviously depends upon the eradication of disability, we must recognize this perspective as colored by histories of ableism and disability oppression.”¹⁹

¹⁷ Akemi Nishida, “Understanding Political Development through an Intersectionality Framework: Life Stories of Disability Activists,” *Disability Studies Quarterly* 36, no. 2. (2016).

¹⁸ Alison Kafer, *Feminist Queer Crip* (Bloomington: Indiana University Press, 2013), 9.

¹⁹ *Ibid*, 3.

Ableism is generally understood as disability discrimination. However, ableism is much further reaching than this. As explained in a working definition by Talila Lewis, ableism is as follows:

a system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence and excellence. These constructed ideas ... are deeply rooted in anti-Blackness, eugenics and capitalism. This ... leads to people and society determining who is valuable or worthy based on people's appearance and/or their ability to satisfactorily produce, excel & 'behave.'²⁰

Importantly, Lewis also notes that one does not have to be disabled to experience ableism. In fact, ableism's connections to classism, racism, homophobia and other forms of oppression, disable large swaths of the population and make it a valuable tool for cross-movement analysis. Further, "disability is not a fixed state of attribute but exists in relation to assemblages of capacity and debility, modulated across historical time, geopolitical space, institutional mandates, and discursive regimes."²¹ Disability is often a political category and is not as rooted in bodily experiences as one might initially think. Instead, disability and ableism are often used to enforce political hierarchies. These views of ableism and disability point towards a more expansive view of disability, looking at the ways in which certain communities or populations, such as Appalachians, become othered in ways that expand beyond the experiences of disability itself.

²⁰ Talila Lewis, "Longmore Lecture: Context, Clarity & Grounding," blog post, March 5, 2019, <https://www.talilalewis.com/blog/longmore-lecture-context-clarity-grounding>.

²¹ Jasbir K. Puar, *The Right to Main: Debility, Capacity, Disability* (Durham, NC: Duke University Press, 2017), xiv.

Black Lung

On February 26, 1969, 2000 striking miners rallied in Charleston, West Virginia, chanting “No law, no coal” in front of the state legislature.¹ Wildcat walkouts in the coal mines had begun a week earlier, and continued on for weeks, necessitating the closure of dozens of mines across the state.² As strikes spread across the state over several days, thousands of miners refrained from work, shutting down the coal industry. By the day of the rally, over 30,000 miners were on strike.³ Two days later, the *Beckley Post-Herald* reported that the number of striking miners had increased to 40,000, and the coal industry had suffered \$4.5 billion in losses.⁴ These strikes went against the wishes of the United Mine Workers of America (UMWA), who claimed the strikes violated the union’s contract and unsuccessfully demanded that the miners return to work immediately.⁵

The law in question would make coal worker’s pneumoconiosis, commonly known as black lung disease, a compensable occupational illness. To the detriment of mine workers, black lung disease was not properly recognized and treated, disabling many. A 1969 international research conference concluded that one out of ten coal miners had black lung disease, and more had other respiratory diseases, such as chronic bronchitis and emphysema.⁶ Anyone who had worked in or around a coal mine for at least two years and developed

¹ “Governor Says He’ll Okeh Act on Black Lung,” *Beckley Post-Herald*, February 27, 1969, 1.

² “Capital Rally Slated Today by Black Lung Association,” *Beckley Post-Herald*, February 26, 1969, 1.

³ “Governor Says He’ll Okeh Act.”

⁴ “Coal Industry Files Suit Against the UMW.” *Beckley Post-Herald*, February 28, 1969, 1.

⁵ Stop Strike, UMW Urged,” *Beckley Post-Herald*, February 26, 1969, 1.

⁶ “1 Miner in 10 has Black Lung,” *Beckley Post-Herald*, September 14, 1969, 2.

breathing challenges would be presumed to have black lung under the new state law, with the burden of proof being removed from the miner and placed on the coal operator.⁷

Bill Worthington, disabled miner and former president of the activist group the Black Lung Association, tells his story of black lung leading up to these events:

About 1953, I believe, a doctor by the name of Dr. Donald Rasmussen who did research for the Appalachian Regional Commission began to study miners. He found out that we didn't have 'miner's asthma,' or walking consumption or any such thing, but we were suffering from pneumoconiosis. We cut the term short to say, simply, Black Lung, a respiratory disease. Finding out from this crusading doctor what was actually going on, we began to get pretty angry. Our people were dying. They weren't getting benefits. Coal companies were making millions of dollars off of us, and then, when we got too sick to work, they said we had 'miner's asthma' for which there's no compensation. You were just out. You went to the poor house or started begging.⁸

The Black Lung Association (BLA), along with other organizations, such as Miners for Democracy and the Disabled Miners and Widows, brought disability concerns to their platforms, often in the process of challenging the shortcomings of the United Mine Workers of America and expressing discontent about union leadership. This chapter discusses the way in which these organizations incorporated disability rights into their platforms and reconceptualizes black lung protests as a previously unrecognized event in disability history.

⁷ "Local Delegates to Introduce Bill to Aid Miners: VISTA Worker Advocates Changes," *Beckley Post-Herald*, December 29, 1968, 26.

⁸ Quoted in Alice Lynd and Robert Staughton Lynd, *Rank and File: Personal Histories by Working-Class Organizers* (Princeton: Princeton University Press, 2014), 287.

Historians acknowledge that “recognition of black lung as a legitimate, disabling, and compensable occupational disease required the active intervention of coal miners themselves,”⁹ and I contend that this intervention can also be understood through the lens of disability, expanding our understandings of Appalachian social movements.

The black lung movement has primarily been analyzed by historians in terms of class, labor, and power dynamics. These analyses recognize black lung as an important social movement but fail to fully engage with the category of disability, even though disability is crucial to their narrative. Barbara Ellen Smith shows the power of the medical-legal complex and argues that “the recognition that occupational lung disease was rampant among coal miners did not evolve of its own accord within the boundaries of medical science. It was forced on the medical establishment through the decidedly political actions of coal miners themselves.”¹⁰ Similarly, Alan Derickson discusses the systems that produce and define disability through focusing on the legal and political stakeholders.¹¹ Disability, at least in terms of medical care and occupational benefits, was highly important, but rather than discussing disenfranchisement of the miners on the basis of disability, analyses of the black lung movements have tended to focus on class relations or legal history.¹² Among industries, coal mining was one of the most disabling, considered to have one of the worst occupational

⁹ Barbara Ellen Smith, *Digging Our Own Graves* (Philadelphia: Temple University Press, 1987), 5.

¹⁰ Smith, *Digging Our Own Graves*, 30.

¹¹ Alan Derickson, *Black Lung: Anatomy of a Public Health Disaster* (Ithaca, NY: Cornell University Press, 1998).

¹² E.g., Daniel J. Curran, *Dead Laws for Dead Men: The Politics of Federal Coal Mine Health and Safety Legislation* (Pittsburgh, PA: University of Pittsburgh Press, 1993); Richard A. Brisbin, Jr., *A Strike Like No Other Strike: Law and Resistance During the Pittston Coal Strike of 1989-1990* (Baltimore, MD: Johns Hopkins University Press, 2002).

safety records of the mid-20th century and lacking the occupational disability compensation benefits of other industries.¹³

These secondary sources show how disability is a socially-constructed category, a bodily reality that interfaces with legal interventions and categories. Taking up disability in this way allows us to see how disability protests have been an important part of Appalachian history, without glamourizing the pain and suffering that were widespread throughout the coalfields. Instead, disability is a category that is politically important and coalesced workers to fight for disability rights and benefits.

The disability rights movement is typically understood through events such as the 504 sit-ins in San Francisco and the crawl up the steps of the Capitol in Washington, D.C. to demand the passage of the Americans with Disabilities Act.¹⁴ Those in the disability rights movement have typically identified as having congenital disabilities, as opposed to disabilities acquired later in life. Disabled veterans returning from both the World War II and Vietnam provided additional numbers and pressure on the federal government to take action.¹⁵ The disability rights movement relied on a three-pronged approach, described as “lobbying in the legislative halls, litigating in the courts, and agitating on the streets.”¹⁶ In addition to drawing energy from the anti-war movement, disability rights protesters framed

¹³ Brit Hume, *Death and the Mines: Rebellion and Murder in the United Mine Workers* (New York, Grossman Publishers, 1971), 54.

¹⁴ Kevin Cullen, “An Act of Empowerment: Disability Rights Bill Marks Watershed Movement,” *The Boston Globe*, July 1, 1990.

¹⁵ Steven A. Homes, “Disabled Americans Assert Self on Political Scene,” *Stevens Point Journal*, March 21, 1990, 4.

¹⁶ Cullen, “Act of Empowerment,” 19.

themselves as the next civil rights group, and collaborated with African American activists. A delegate of the National Paraplegics Convention prior to the passing of Section 504 of the Rehabilitation act describes how she learned to compare the civil rights of “crips” to those of African Americans, who had also been denied education, transportation, and jobs.¹⁷ Instead of positioning themselves as victims of their disabilities, activists understood their disabilities as being socially stigmatized, creating attitudinal barriers that were just as important as any physical barriers.¹⁸ Disabled activists argued that disabled people needed the services and means to fully participated as integrated members of society.

Black lung organizing is largely excluded from the typical history of disability rights.¹⁹ In addition to asking for accommodations for disabilities, disabled coal miners and their families fought to be recognized as disabled and receive the benefits that would allow an adequate standard of living. Broadly conceptualized, black lung organizers wanted the disabled to achieve political power, a goal which resonates with the later, and better known, disability rights actions. Following disability historian Kim E. Nielsen, who asserts that disability, and conceptions thereof, helps understand American history in new ways,²⁰ I propose reframing of the black lung movement as disability rights.

¹⁷ Sam Hodges, “Able to Lead – the Beverly Chapman Story,” *The Orlando Sentinel*, July 24, 1988, F-5.

¹⁸ William L. Rush, “Disabled Victims of Society’s Attitudes,” *Lincoln Journal Star*, March 26, 1985, 10.

¹⁹ E.g., James I. Charlton, *Nothing About Us Without US: Disability Oppression and Empowerment* (Berkeley: University of California Press, 2000); Joseph P. Shapiro, *No Pity: People with Disabilities Forming a New Civil Rights Movement* (New York: Random House, 1993); Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia, Temple University Press, 2001).

²⁰ Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2012), xi-xii.

This is a move some scholars have made in examining coal mining in the United Kingdom.²¹ Drawing on oral history interviews with coal miners in Wales, Arthur McIvor and Ronald Johnston write that “[coal] miners might offer an archetypal case study of the power and agency of the disabled, and one which demonstrates the complexity of lived experience and the limitations of any simplistic model of social exclusion and oppression.”²² I extend McIvor and Johnston’s assertion to Appalachia, where coal miners had less stringent workplace safety laws and occupational compensation programs than across the Atlantic. An occupational health doctor compared coal mining in the United States with that in other countries and concluded that “if American [coal] operators would make more jobs for dust control, repair work and safety maintenance, ‘productivity’ per man would probably be less. But so would the crippling and killing of men.”²³

Class and power relations suppressed the ability to provide effective disease recognition and treatment for miners. Nineteenth century pulmonary specialists on both sides of the Atlantic identified black lung as an illness and linked it to coal dust exposure in the workplace. Despite this knowledge, doctors in the coalfields and the mining industry assumed a markedly skeptical stance, taking the approach that breathing difficulties in coal miners was normal, thus not requiring medical intervention.²⁴ Louisville, Kentucky doctors argued that air pollution from coal dust was not cause for concern because even though coal

²¹ E.g., Alexandra Jones, “‘Her Body [was] like a Hard-Worked Machine’: Women’s Work and Disability in Coalfields Literature, 1880-1950,” *Disability Studies Quarterly* 37, no.4 (2017).

²² Arthur McIvor and Ronald Johnston, *Miners’ Lung: A History of Dust Disease in British Coal Mining* (Burlington, VT: Ashgate, 2007), 307.

²³ Wesley Mason, “Health and Safety in Other Lands,” *Black Lung Bulletin* 2, no. 5, November 1971, 5.

²⁴ Smith, *Digging Our Own Graves*, 17.

miners' lungs turn black from breathing the dust, "they seem to get along without any unusual trouble."²⁵ One miner said that he and his coworkers were told that breathing in coal dust was healthy, even beneficial.²⁶ Even when doctors and coal companies recognized breathing difficulties as an illness, they often ignored that coal dust was the causative mechanism. Aside from dust, other proposed causes for respiratory disease were underground gasses, stress, and the subterranean work environment. Proving disablement was further complicated by changing technology, which allowed for more precise diagnostic standards and testing, and an increased reliance on x-ray imaging - an imperfect marker of black lung.²⁷

Additionally, most medical care in the coal fields was provided by company doctors, who had blatant conflicts of interest when it came to addressing occupational disease and disability, which inevitably impacted the types of medical care and treatment offered. Most doctors came from outside the region and were seen as being exploitive, just like the coal companies for which they worked.²⁸ In what is commonly known as the Boone Report, health investigators studied 260 mines to assess both health services and hazards to wellbeing in the communities.²⁹ Though many investigators had preconceptions that lead them to focus on sanitation and living standards instead of mining conditions, the final report still spoke to

²⁵ "Soot Yourself, But Will Your Chest Ignore It?" *Louisville Courier-Journal*, January 8, 1949, 9.

²⁶ Lynd and Lynd, *Rank and File*, 287.

²⁷ Smith, *Digging Our Own Graves*, 151.

²⁸ Helen Lewis, 1971, "Medicos and Mountaineers: The Meeting of Two Cultures." Edited version of speech given at the Appalachian Regional Hospital's Spring Scientific Session, Bristol, Virginia, April 22. AC.103: Helen Matthews Lewis Papers, W. L. Eury Appalachian Collection, Appalachian State University, Boone, NC.

²⁹ Joel T. Boone, *A Medical Survey of the Bituminous-Coal Industry: A Report of the Coal Mines Administration* (U.S. Department of the Interior: Washington, D.C., 1947).

the lack of appropriate occupational-based medical care, stating that few physicians were familiar with the risks of underground labor and were loath to disclose the extent of occupational disease. Coal operators argued that the Boone Report was inaccurate, with an unrepresentative sample of mining towns and focusing on sanitation programs that were endemic across America and not unique to rural Appalachia.³⁰

The Boone Report criticized the United Mine Workers, the miners' labor union, for their lack of leadership on health and safety issues and pushed the union to better incorporate healthcare into its platform.³¹ Following the Boone report, the federal government undertook additional surveys to establish the extent of black lung throughout Appalachia; however these were critiqued as ineffective.³² Furthermore, increasing numbers of scientific studies out of the United Kingdom more closely linked black lung to dust exposure. Though the U.S. government took little action in light this of new information, the new studies did embolden litigation, which then led to state-level workers' compensation laws that recognized some cases of black lung but did not reach everyone affected.

Miners were concerned that the UMWA no longer acted in their best interests. Rank and file miners worried that union leadership was no longer representative and democratic, and the challenges of black lung disease only exacerbated these tensions. A *Wall Street Journal* report found that miners had little recourse if their compensation claim was denied, and that the annual pension for a disabled coal miner was \$1380, seemingly paltry in

³⁰ "Mining Town Survey Hit: Coal Trade Group Says Public Misled by Federal Survey" *The Berkshire Eagle*, April 21, 1947, 3; "Claims Report on Coal Mining Towns Distorted," *New Castle News*, May 8, 1947,

³¹ Derickson, *Black Lung*, 116.

³² "Nader Charges U.S. Efforts on Disease 'Inept,'" *Louisville Courier-Times*, January 1, 1969.

comparison to the \$20-30,000 retirement pension for UMWA leaders.³³ Feeling that the union was bloated and inefficient, and often downright unfair, organizations formed to challenge the authority of the UMWA and address the union's shortcomings.

The Black Lung Association formed in West Virginia in January of 1969. "Comprised of rank-and-file miners, community activists, liberal politicians, and the Committee of Physicians, the [Black Lung Association] campaigned for workers compensation for West Virginia black lung victims through a series of rallies, demonstrations and marches."³⁴ Initially, a West Virginia organization focused on a state-level compensation law discussed at the beginning of this paper, the BLA grew across Appalachia to campaign for federal-level action. The BLA was one of several grassroots organizations that formed around the issues of black lung and occupational compensation. The Association of Disabled Miners and Widows formed around the same time as the BLA, and Miners for Democracy emerged as a reform group in the union in the early 1970s. These groups had similar aims of critiquing union leadership and campaigning for black lung compensation. In the opinion of opposing groups, union leadership did not do enough to ensure black lung compensation and had become an inefficient tool to ensure the health and safety of its members.

Dr. Hawey Wells, a pathologist, traveled with Drs. Donald Rasmussen and J. E. Buff as part of an Appalachian Research Commission-funded project on black lung diseases. In a dramatic public display, Dr. Wells held up a thin, dry slice of lung tissue, before closing his

³³ Ralph de Toledano, "Labor Keeps Lobby Muscle; Tide Turning," *Dixon Evening Telegraph*, January 6, 1969, 4.

³⁴ Richard Fry, "Dissent in the Coalfields: Miners, Federal Politics, and Union Reform in the United States, 1968–1973," *Labor History* 5, no. 2 (2014): 175-176.

fist around it, sending it crumbling to the ground, pulverized.³⁵ "Dust, dust, dust, coal dust," the doctor was quoted as saying. "The tissues are full of it. So are yours. You breathe coal dust every working day, at levels of 3000 milligrams per cubic meter of air."³⁶ The Black Lung Association helped organize this presentation to inform miners about black lung disease and compensation, building a community of disabled miners.

In addition to legislating and lobbying, the Black Lung Association also helped disabled miners navigate the social security benefits process. A 1972 self-published booklet by the Black Lung Association details the process of navigating a social security claim for black lung benefits and what actions one should take in the case that one's claim is denied.³⁷ This illustrated guide encourages miners to seek help from the Black Lung Association through detailing the story of "Black Lung Bill," a coal miner who "can't work because he can't breathe too good."³⁸ Throughout the booklet, Bill attends Black Lung Association meetings, applies for federal black lung benefits, gets denied by the Social Security Administration, and appeals with the help of his friends. At the end of the booklet, Bill concludes, "I got my benefits but I'll keep on fighting until the disabled miners and widows and all the poor and working people gets [sic] justice. Let's get together and make our voices heard!"³⁹ Though this narrative focuses on the social security benefits process, it also shows

³⁵ Joseph A. Loftus, "Dramatic Demonstration of Mines' 'Black Lung,'" *The Salina Journal*, January 7, 1969, 6.

³⁶ "Miners Rally to Support Law Fighting Black Lung," *The Louisville Courier-Journal*, January 7, 1969, B5.

³⁷ Black Lung Association, "Black Lung Bill Battles Social Security: What to do when Denied Your Black Lung Benefits," (Charleston, WV), W. L. Eury Appalachian Collection, Appalachian State University, Boone, NC.

³⁸ *Ibid*, 1.

³⁹ *Ibid*, 14.

a concern for the broader social welfare, questioning “why aren’t the mines safe and dust free in the first place?”⁴⁰

Several factors led to an increased interest in black lung disease, creating the conditions for the Black Lung Association’s formation. In 1968, the Farmington, Virginia mine explosion killed 78 miners and caused public grief and outrage. 1968 was a crucial year, perhaps the tipping point, a year in which coal miners expressed a great deal of anger and resentment, drawing national interest. Smith credits this year as bringing “a violent climax to nearly a decade of social upheaval [as] coal miners and their families began to act collectively on the black lung problem.⁴¹ The Association of Disabled Miners and Widows were one of the first official organizations to form around the black lung issue. “[They] doubted the union welfare plan would ever meet [their] needs [and] proposed changes in West Virginia’s tightly drawn workers’ compensation law.”⁴²

At the end of December 1969, President Richard Nixon signed the Federal Coal Mine Health and Safety Act, responding to miners’ demands. This act set a maximum acceptable dust level, included provisions for x-ray examinations for miners with black lung, and provided affected workers with the option of transferring to a less dusty position in the mines. The UMWA called this an “outstanding victory.”⁴³ Yet, the Bureau of Mines, responsible for enforcing this act, was soon left without a director. The Nixon administration

⁴⁰ Ibid.

⁴¹ Smith, *Digging Our Own Graves*, 108.

⁴² Derickson, *Black Lung*, 146.

⁴³ UMWA, *Black Lung* (UMWA), 35.

denied that this was due to differences in opinion between the former director, John O’Leary and the soft coal industry; however, sources believed that it was industry opposition that removed O’Leary and one of his assistant directors from their posts.⁴⁴ By August of 1970, the Bureau had been without a director for five months, and UMWA President Boyle commented that affairs there resembled a “headless horseman groping blindly for direction and purpose,” blaming Nixon for the lack enforcement of the Coal Mine Health and Safety Act.⁴⁵

Though it included regulations for regular mine safety inspections, precisely one year after it was signed into law, another explosion killed 38 miners in Hurricane Creek, Kentucky, the most fatal disaster since Farmington. Richard Fry contends that this Bureau was not effective, nor was it ever intended to be, as it had little power to both inspect or force compliance with regulations.⁴⁶ Regulation and inspection of mines was uneven, and the Bureau drew criticism for being in too close a relationship with the mining industry.⁴⁷ Indeed, the newly appointed director of the Bureau of Mines was quoted as saying, “We can expect one of these every year,” in regards to the Hurricane Creek disaster.⁴⁸ Once again, miners mobilized, including a letter writing campaign to the Bureau of Mines, an agency

⁴⁴ “Administration Denies Mine Chief Ousted,” Grand Junction, CO *The Daily Sentinel*, March 15, 1970, 6.

⁴⁵ Milton Jaques, “Boyle Blames Nixon for Mines’ Plight: UMW President Raps Health Act Enforcement,” *Pittsburgh Post-Gazette*, August 18, 1970, 9.

⁴⁶ Fry, “Dissent in the Coalfields,” 175.

⁴⁷ Ben A. Franklin, “Bitter Dispute Surfaces over Mine Safety Laws,” *The Dominion News*, April 24, 1970, 1.

⁴⁸ Thomas N. Bethell and Davitt McAtteer, “The Pittston Mentality: Manslaughter on Buffalo Creek,” Charleston, WV *Sunday Gazette-Mail*, June 11, 1972, 4D.

within the Department of the Interior, responsible for overseeing the Coal Mine Health and Safety Act.

Through all this, the United Mine Workers of America took a rather hands-off approach. Despite pressure from constituents, at the 1968 UMWA convention, union President Tony Boyle failed to call for workplace changes that could have prevented black lung, instead urging districts to take up the cause on a state-by-state legislative basis.⁴⁹ The UMWA claimed that it was a leader in passing state-level compensation laws and had written safety provisions into its contracts.⁵⁰ Despite these laws and safety measures, black lung remained a serious concern for many miners, who felt that the union was not doing enough to protect workers' health.

Discontent over the UMWA was growing as president Tony Boyle “was more concerned with the economic interests of the coal operators and his own financial advancement than [with] the welfare of the union’s members.”⁵¹ An opinion piece describes the union as becoming cozy with the coal operators, impacting the efficacy of the Bureau of Mines and the safety of mineworkers.⁵² The Association of Disabled Miners and Widows felt that pension and labor funds were not administered fairly and found many disgruntled miners throughout Appalachia agreed with a critique of the union.⁵³

⁴⁹ “Resolution” 34.

⁵⁰ UMWA, *Black Lung*, 1.

⁵¹ Fry, “Dissent in the Coalfields,” 174.

⁵² Jack Anderson, “52 Coal Miners are Dead,”

⁵³ Julia Sadd, “Pension Fund Use Splits UMW Groups,” *The Pittsburgh Press*, July 2, 1967, sect. 3, 2.

Reform candidate Joseph “Jock” Yablonski campaigned against Boyle for the presidency of the 220,000 member UMWA in the December 1969 election, running on a platform to increase representation of rank-and-file miners.⁵⁴ In a heated lead-up to the election Yablonski drew both sharp criticism from Boyle⁵⁵ and physical attacks on the campaign trail from Boyle’s supporters.⁵⁶ Yablonski expressed confidence for a victory if the election was conducted fairly, yet was skeptical of the possibility.⁵⁷ After a bitter election, Boyle garnered nearly twice the votes as Yablonski, who contested the election results and threatened a nationwide strike.⁵⁸ Shortly after the New Year, Yablonski was murdered in his Clarksville, Pennsylvania home, along with his wife and daughter.

Yablonski’s assassination strengthened feelings of unrest and political activism in the coalfields and led to the inception of the reform group, Miners for Democracy, which formed shortly after his death. One of the group’s first gatherings was a tribute to Yablonski on the traditional miners’ holiday of April 1st, led by Yablonski’s two sons, along with a group of miner’s widows who called themselves “Widows for Yablonski.”⁵⁹ The UMWA’s response to the Miners for Democracy was to form a commission to investigate the insurgent organization, saying that union members were permitted to dissent, but not for the purpose of

⁵⁴ “His Opponent is No Stranger to Mining’s Rough and Tumble,” Hackensack, NJ *The Record*, December 3, 1969, C 15.

⁵⁵ “Boyle Campaign Tears Page from John L.’s Fiery Book,” Hackensack, NJ *The Record*, December 3, 1969, C 15.

⁵⁶ Dave Hurst, “Elections Rigged, Yablonski Says,” *Southern Illinoisan*, November 3, 1969, 3.

⁵⁷ Ibid.

⁵⁸ “UMW Reform Needed,” *The Pittsburgh Press*, December 30, 1969, 1.

⁵⁹ Edward Verlich, “Miners Vow Self-Rule as Tribute to Their Man ‘Jock,’” *The Pittsburgh Press*, April 2, 1970, 2.

forming a movement within its organization.⁶⁰ The rank-and-file members of the UMWA pushed for organizational leadership that took concerns about black lung disability seriously.

It took an additional round of campaigning to enact widespread, meaningful change. The Black Lung Association continued to organize, distributing their *Black Lung Bulletin* beginning in 1970. This monthly publication provided news on strikes, the compensation process, and mine safety. Initially only a few people interacted with the publication, which was available for a small fee.⁶¹ An editorial during one of the first issues details the issues the Black Lung Association was up against:

The Federal Mine Health and Safety bill is not being enforced; election abuses and the murder of Jock are clear evidence that we do not have democracy within our union; grievances are sold out by union officials; and many retired or disabled miners are without compensation or medical and retirement benefits.⁶²

The Black Lung Association understood there to be no strong leadership over the mines and miner and positioned themselves as filling this void. This editorial also details some failures by the Disabled Miners of southern West Virginia and the Miners for Democracy in representing the entire reform movement or organizing effectively against the coal operators.

⁶⁰ “Rebel Probe Set...Battle Lines Formed in Miners’ Union,” *The Daily Notes* (Canonsburg, PA), October 1, 1970, 1.

⁶¹ “This is Your Newsletter,” *Black Lung Bulletin* 1 no. 2, July 1970, 4.

⁶² “The Need: Unity and Leadership,” *Black Lung Bulletin*, 1, no. 4, September 1970, 1.

As the Black Lung Associate grew, new chapters formed,⁶³ expanding the movement from its West Virginia birthplace across Tennessee, Kentucky, Virginia, and Pennsylvania.

Statistics show the extent of black lung disease, and the scope of claims denials. According to the UMWA, the commonly accepted figure for the number of active miners with black lung disease in the late 1960s was 125,000.⁶⁴ As of early February 1971, the Social Security Administration had received over a quarter million claims for black lung benefits.⁶⁵ Of these, 39% had been paid, 34% had been denied, and 27% were waiting for their claim to be reviewed. Notably, the approval rate was 56% in Pennsylvania, significantly higher than the national average.⁶⁶ The Black Lung Association explains that this is because physicians in Pennsylvania do not rely solely on x-ray evidence, noting that most of the people who were denied, were denied because their x-ray did not show black lung. “Doctors who know say an x-ray will not always show Black Lung,” they write in their bulletin, claiming that Social Security’s reliance on x-ray imaging went against the Mine Health and Safety Law and was used to unfairly deny claims.⁶⁷

The emphasis on x-ray testing was one of the Black Lung Association’s concerns with how the Social Security Administration managed black lung claims. The Association submitted a written list of questions to Social Security in March 1972, and seven

⁶³ “New BLA Chapter!,” *Black Lung Bulletin* 1, no. 10, March 1971, 1.; “Tennessee Chapter Organizes” *Black Lung Bulletin* 2, no. 2, August 1971, 4.

⁶⁴ UMWA, *Black Lung*, 1.

⁶⁵ “March on Washington”, *Black Lung Bulletin*, special edition, June 1971, 2.

⁶⁶ *Ibid.*

⁶⁷ *Ibid.*

representatives from the Beckley chapter of the BLA met with Social Security officials to address these issues. Levi Daniel, one of these representatives, is quoted as saying “we have questions because people in the organizations come up with problems in their claims.”⁶⁸

Black Lung Association members, known as lay advocates, were trained by the Appalachian Research and Defense Fund to assist in the process of requesting benefits and understanding legalese. Lay advocacy became like a job for many and provided a sense of pride, especially as many of these individuals did not have a high level of formal education.⁶⁹ The concerns expressed by the lay advocates in this meeting with the Social Security Administration centered around evidence and testing. In addition to debates about the accuracy of x-rays, the BLA felt that the Social Security Administration failed to consider and inform claimants about the range of testing options, such as blood gas studies, which might prove better evidence during the compensation process.⁷⁰

The Black Lung Association also lobbied in Washington for union reform. In February 1971, more than 450 miners from three states traveled to support the lobbying effort led by the Miners for Democracy. The *Black Lung Bulletin* reports that miners got a mixed reaction in D.C.: while West Virginia Representative Ken Hechler spent all day helping the men navigate Congress, others made up excuses to avoid meeting or were openly hostile.⁷¹ The Black Lung Association participated in several trips such as this one,

⁶⁸ “BLA vs SSA” *Black Lung Bulletin* 2, no. 10, April 1972, 3.

⁶⁹ Smith, *Digging Our Own Graves*, 163.

⁷⁰ Ibid.

⁷¹ “Special Report: Miners in Washington,” *Black Lung Bulletin* 1, no. 10, March 1971, 1-2.

identifying the Social Security Administration, the United Mine Workers, and President Nixon as targets of lobbying.

The United States House of Representatives voted on the Black Lung Amendments and passed with them overwhelming support, 312-78, in the fall of 1971.⁷² These amendments consisted of several provisions that extended benefits and eligibility and determined that x-rays were not allowed as the sole evidence of black lung. These amendments were contested when the bill went to the Senate, though the bill's protections for orphans and widows were strengthened in committee.⁷³ The Senate version of the bill, passed unanimously on April 12, 1972, contained important provisions and the BLA expressed their support for this version of the bill, which was less favorable to the coal operators.⁷⁴ The BLA encouraged its members to write to President Nixon and encourage him to sign the Senate version of the bill into law.⁷⁵

Nixon signed the Black Lung Benefits act the following month, thanks to impressive grassroots organizing. The BLA reported that hundreds of their members lobbied in Washington, protested at local Social Security offices, and wrote letters to their representatives.⁷⁶ Smith describes the 1972 amendments as “a clear-cut political victory by the black lung movement—much more so than the West Virginia compensation law for which the movement is known.”⁷⁷ Leaders from the Black Lung Association played a strong

⁷² “Victory!!,” *Black Lung Bulletin* 2, no. 5, November 1971, 1.

⁷³ “B. L. Bill in Danger,” *Black Lung Bulletin* 2, no. 9, March 1972, 5.

⁷⁴ “Approval Awaited,” *Black Lung Bulletin* 2, no. 10, April 1972, 2.

⁷⁵ Ibid.

⁷⁶ “Nixon Gives In!!,” *Black Lung Bulletin* 2, no. 11, May 1972, 1.

⁷⁷ Smith, *Digging Our Own Graves*, 173.

part in shaping this bill, which eliminated the long fought-over rule that claims could not be denied on the basis of a negative x-ray alone. This bill also extended benefits and made them retroactive to the end of 1969, included provisions to fund treatment and research for black lung, and provided a review of previously denied claims.

The fight for black lung benefits was not over. The Black Lung Association continued to shape this bill after it was signed into law, demanding to have a say in writing the Social Security regulations for black lung claims. The Black Lung Association said that they couldn't "count on [the Social Security Administration] doing what they say they will do, or even doing what the law says they must do."⁷⁸ The BLA demonstrated at local Social Security offices in Kentucky, Virginia, and West Virginia to pressure them into providing an advance copy of the regulations.⁷⁹ The BLA then worked with a team of doctors and lawyers to maximize benefits to disabled miners. Members of the BLA were concerned, seemingly with good reason, that the Social Security Administration would fail to interpret the Black Lung Act in the manner intended by Congress, and the regulations would be unfair. The comparative ease of getting benefits for older miners angered the BLA the most.⁸⁰ Ultimately, the Social Security Administration's black lung regulations became so complex and convoluted that it was nearly impossible to understand them. While many claimants were awarded benefits under the interim regulations, once the permanent regulations were in effect, the denial rate climbed.⁸¹

⁷⁸ "Listen to Us, SSA!," *Black Lung Bulletin* 3, no. 1, June 1972, 1.

⁷⁹ "A Continuing Story: BLA VS SSA," *Black Lung Bulletin* 3, no. 3, August 1972, 1.

⁸⁰ Ibid.

⁸¹ Smith, *Digging Our Own Graves*, 179.

With the Black Lung Act passed, the UMWA showed interest in the BLA and its talking points, likely influenced by the forthcoming election. The BLA supported Arnold Miller, the Miners for Democracy-backed candidate, and refuted the UMWA's claims that it had helped pass the Black Lung Act. When one UMWA official claimed that "It was largely due to the UMWA's lobbying efforts that the federal Black Lung Benefits Act of 1972 became law," BLA president, Bill Worthington disagreed, "[They] haven't helped get black lung benefits, and they're not really helping write the new regulations. They are doing an injustice to the Black Lung Association."⁸²

Arnold Miller won the UMWA presidency in the December 1972 election. Miller faced a difficult job. Upon taking office, he found that records were in disarray and programs were riddled with insufficiency and fraud.⁸³ Though not all of the miners welcomed his leadership, he made significant changes to the union within the first six months of his presidency, including expanding the occupational health program and union safety department.⁸⁴ Miners for Democracy, considering themselves to have successfully reached their aims, disbanded after Miller's victory. Organizers believed that Miners for Democracy had become the union, and there was no need to continue a fundamentally divisive group.⁸⁵

Despite high hopes, the Miller presidency was beset by challenges. His own inexperience, and that of many of his officials, was a major stumbling block. Miller

⁸² "UMW Moves in on BLA," *Black Lung Bulletin* 3, no. 3, August 1972, 3.

⁸³ Nick Kotz, "Miller is Putting Democracy Back in UMW," *The Philadelphia Inquirer*, July 10, 1973, 1.

⁸⁴Ibid, 4.

⁸⁵ Interview with former UMWA staff person, Washington, D.C., September 24, 1980, quoted in Smith, *Digging Our Own Graves*, 186-187.

attempted to work with coal operators, and after strikes in 1974, the coal operators offered a generous settlement, which they hoped would put an end to wildcat strikes and stabilize production⁸⁶ Despite this agreement, a gamble on the part of the coal operators, the wildcat strikes in the winter of 1977-78, as Congress debated still further black lung reform, were the longest in the history of the UMWA. The coal operators returned to the negotiating table, this time with a lengthy list of demands, prepared to wait out the strike.⁸⁷ The UMWA rejected these demands, with the strikes garnering nationwide attention amid fears of power shortages. Though the coal operators claimed that they “bent over backwards”⁸⁸ to meet the demands of the union, Smith describes a more strident approach, which eventually led to the UMWA ratifying “unmistakably regressive” provisions.⁸⁹ Among these, the Welfare and Retirement Fund was dissolved and replaced with private insurance coverage.

The Miller election also brought upon the decline of the Black Lung Association. While the Black Lung Association was useful when the UMWA would not hear miners’ concerns, having union leadership that was sympathetic to the black lung issue created confusion about the roles and relationship of the two organizations. As BLA members retired or got claims approved, they took a less active role in the organization. Younger workers were less concerned about the seemingly distant problems of chronic lung disease, further weakening the Black Lung Association as time went on.

⁸⁶ John P. Moody, “Miners Approve the Contract to End Strike,” *Pittsburgh Post-Gazette*, December 5, 1974, 1.

⁸⁷ Smith, *Digging Our Own Graves*, 202

⁸⁸ Bituminous Coal Operators Association, advertisement, “An Open Letter to the American People, The Congress, The President,” *Chicago Tribune*, March 8, 1978, 31.

⁸⁹ Smith, *Digging Our Own Graves*, 202.

Both the BLA and UMWA experienced their setbacks and challenges, as well as notable successes in shaping the course of the coal mining industry in central Appalachia. The BLA's legacy has continued. In 1988, the Virginia Black Lung Association formed out of shared frustrations about the disability process, functioning more like a therapy or mutual aid group.⁹⁰ Much more recently, the BLA has responded to an uptick in the number of black lung cases and the potential end of the Black Lung Disability Trust Fund through renewed lobbying efforts.⁹¹

As scholars counter stereotypes of Appalachian fatalism by examining resistance movements in Appalachia,⁹² discussions that contribute to cross-issue solidarity build the ways Appalachian people are understood as politically engaged, confronting stereotypes about fatalism and culture of poverty. The black lung movement brings together disability and labor movements, which have not always had an easy alliance. The impacts of labor on workers' health is a concern for both labor and disability rights activists and scholars, yet there are fundamental differences between these two camps. Participation in the labor force is not always accessible, as disabled people face challenges in finding and maintaining a job due to "segregated education, poor job training, low expectations, inaccessible transportation, employer disparagement, outright discrimination, and harassment by other employees."⁹³

⁹⁰ Marilyn Carroll, "Appalachian Coal Miners Combine Mutual Help and Advocacy," *Public Health Reports* 114, no. 4 (1999).

⁹¹ Kevin Riddler, "The Black Lung Association Responds to the Deadly Disease's Rise," *The Appalachian Voice*, October 11, 2019. <http://appvoices.org/2019/10/11/the-black-lung-association/>.

⁹² E.g., Jessica Wilkerson, *To Live Here You Have to Fight: How Women Led Appalachian Movements for Social Justice* (Urbana: University of Illinois Press, 2019); Stephen L. Fisher, *Fighting Back in Appalachia: Traditions of Resistance and Change* (Philadelphia: Temple University Press, 1993); Stephen L. Fisher and Barbara Ellen Smith, *Transforming Places: Lessons from Appalachia* (Urbana: University of Illinois Press, 2012).

⁹³ Nielsen, *Disability History*, 237.

However, disability scholars and advocates reject the idea that disability is a problem to be solved, while labor activists frame disability as something to be feared or prevented -- a tragedy. While labor and disability rights may overlap, it is an uneasy union. However, in the case of the black lung movement, these factions united successfully to agitate for change.

Black lung organizers joined with workers from southern textile mills claiming brown lung disease and workers exposed to asbestos who suffered from white lung as part of the Breath of Life Organizing Campaign.⁹⁴ This group held the first national Congress for Disabled Workers in 1982 and organized to campaign for better disability benefits. Though all of the workers suffered from some form of respiratory disease, they came from diverse backgrounds, geographically spanning fifteen states, making this an instance of cross-disability solidarity and organizing. The workers were united through their similar experiences of breathing difficulties, problems with lawyers and compensation hearings, and efforts to improve workplace health conditions, as well as sharing a class-based ideology that the workers unfairly bore the brunt of occupational disease.

Thus, disability played an important role in shaping both intra- and inter-regional relationships in Appalachia. McIvor and Johnston state in their oral history studies of mining disabilities in the United Kingdom that most of the disability studies literature “has been constructed from studies of the congenitally impaired, such as those with mental illnesses, those with learning difficulties, and those with loss of faculties such as sight, hearing and speech,” and thus occupational disability and disease is more poorly understood through a

⁹⁴ Bennet M. Judkins, “The People’s Respirator: Coalition Building and the Black Lung Association,” in *Fighting Back in Appalachia: Traditions of Resistance and Change*, ed. Stephen L. Fisher (Philadelphia: Temple University Press, 1993), 224-241.

critical perspective.⁹⁵ Rather than seeing this as a limitation of connecting black lung and other non-occupational disability experiences, I suggest that this is a point for future scholarly expansion that Appalachian Studies is well positioned to address due to the strong history of labor activism in the region.

⁹⁵ McIvor and Johnston, *Miners' Lung*, 275.

Environmental Disability

Central Appalachia has become an environment that is both disabled and disabling. As is the case with black lung, human disability exists in relation to environmental damage. These need to be examined together. The environment of Appalachia has been shaped by extractive industry, which has created both harm to the environment and the beings who live on the land. This environment is not a blank slate but has materially shaped human and non-human relationships. Disability is inherently linked to the environment, but current environmental movements fail to consider this relationship. Instead, disability and disabled people are often positioned as a drain on resources.

An ecological approach to disability recognizes that disability is part of the complex tangle of lifeforms. This also demands that we take human/non-human relationships seriously. Environmental destruction involves grappling with disability on many scales. Sunaura Taylor defines ecological disablement as “profound alterations to the capacities and functionings of an entity or system which limits its ability to sustain itself and others as it previously had and which alters its reproductive capacities.”¹ Taylor challenges us to recognize how disability is co-constituted throughout environmental systems. While remaining critical of the violence that produce disability, disabled lives nonetheless have value.

Taylor herself shows the link between disability and the environment. Taylor lives with birth defects due to military waste. Exposed to trichloroethylene or TCE from

¹ Sunaura Taylor, “Disabled Ecologies: Living with Impaired Landscapes,” Lecture at UC Berkeley, 5 Mar 2019, <https://haasinstitute.berkeley.edu/video-sunaura-taylor-disabled-ecologies-living-impaired-landscapes>.

contaminated groundwater in utero, Taylor has arthrogyrosis, a congenital condition that severely impedes muscle growth and requires her to use an electric wheelchair. Eli Clare describes a conversation he had with Taylor in which she tells him, “I hate the military and I love my body.”² Taylor traces her disablement to the military-industrial complex, which uses solvents containing TCE to remove grease from metal parts in airplanes and to clean fuel lines at missile sites. The question that arises from Taylor and Clare’s conversation is deeply impactful: “How do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds – plant and animal, organic and inorganic, nonhuman and human – while not equating disability with injustice?”³

Cases like Taylor’s are helpful for thinking about how disabled people end up being a cautionary tale, and the value of resisting this narrative. Taylor’s theories of ecological disablement have been instrumental in thinking through disability as harm to broader systems. Disability can be a result of chance, but it often results from violence, war, poverty, and pollution. Disability may stem from injustice, but it is not itself injustice. Eli Clare suggests some of the ways in which disabled bodies become used as cautionary tales, rhetorical props: “arguments against drunk driving, drug use, air pollution, lead paint, asbestos, vaccines, and on and on. So many public campaigns use the cultural fear and hatred of disability to make the case against environmental degradation.”⁴ These arguments reflect

² Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham, NC: Duke University Press, 2017) 256.

³ Ibid.

⁴ Eli Clare, “Notes on Natural Worlds, Disabled Bodies, and a Politics of Cure,” in *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, ed. Sarah Jaquette Ray and Jay Sibara (Lincoln: University of Nebraska Press, 2017), 251-252.

the rampant societal ableism that would seek to prevent disability. Cure is not so straightforward and can sometimes also be an act of violence.⁵

How many of our arguments for justice hinge on placing disability as an undesirable outcome? This happens in Appalachia, too. Many of our movements, those that developed both inside and outside the region, argue against disability and disabled existence. In the case of mining, how are disabled miners used to argue against black lung? The argument here is not that we shouldn't fight against extraction and exploitation, but that we must think more carefully about how we use disabled bodies to further such arguments, and how these arguments leverage disability stigma.

In this chapter, I suggest reconsidering how disability might relate to environmental justice. As is the case with the black lung movement, as well as in extractive industries, such as timber, disability is sometimes a direct result of environmental harm. The environment has become toxic, both literally and metaphorically. Toxins, as byproducts of transnational capitalism, stigmatize marginalized communities, positioning them as queer subjects.⁶ Toxins also emphasize the porous and unbounded nature of bodies and the ways in which materiality circulates between non/human beings.

Building on Mel Chen's work on toxicity, Kelly Fritsch notes the similarities between discourses of toxins and disability: "Toxicity, like disability, is not contained in individually

⁵ Eunjung Kim, *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea* (Durham, NC: Duke University Press, 2017).

⁶ Mel Y. Chen, "Toxic Animacies, Inanimate Affections," *GLQ: A Journal of Lesbian and Gay Studies* 17, no. 2-3 (2011).

bounded bodies; it circulates, altering the life chances of future generations.”⁷ Toxins are deeply embedded in an environment that is not static, but laden with sociocultural political power. Thus, it is not enough to grapple with toxins on the scale of the individual body, to locate disability as an individualized, bodily problem, but to think relationally about naturecultural relationships to disability.

Naturecultures,⁸ a term that highlights the false duality of nature and culture, opens up ways for thinking about both human and more-than-human relationships. Nature, is often the lesser in the nature-culture dualism, and exists as a blank slate for human development.⁹ Recognizing that disability is trans-corporeal, spread between bodies and landscapes, provides a position from which to critique forms of sustainable development and environmental justice that fail to consider the perspectives of disabled people and furthers ableism.

Thinking about disability in a relational manner to the environment requires a rethinking of sustainable development. Mainstream sustainable development fails to challenge entrenched systems in the radical ways that would support disabled people. In fact, mainstream sustainable development “has not been very radical,” and in fact “has sought to refocus existing development initiatives and policy action rather than transform their

⁷ Kelly Fritsch, “Toxic Pregnancies: Speculative Futures, Disabling Environments, and Neoliberal Biocapital,” in *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, ed. Sarah Jaquette Ray and Jay Sibara (Lincoln: University of Nebraska Press, 2017), 374.

⁸ Donna J. Haraway, *The Companion Species Manifesto: Dogs, People, and Significant Otherness*, vol. 1 (Chicago: Prickly Paradigm Press, 2003).

⁹ Stacey Alaimo, *Bodily Natures: Science, Environment, and the Material Self* (Bloomington: Indiana University Press, 2010), 2.

principles or practice.”¹⁰ Mainstream sustainable development, as exemplified by canonical documents such as *Our Common Future* and *Agenda 21*, does not challenge linear notions of capitalist development and unbridled potential, oftentimes at the expense of disabled people. *Our Common Future* urges that sustainability eradicate disability from disadvantaged groups, particularly in Indigenous and Global South locations, a colonizing move that positions the economic North as superior and abled.¹¹

The environmental conservation and wilderness movements have attachments to an idealized, abled, fit, often masculine body. In the United States, the wilderness movement, that emerged in the 19th century, is rooted in classist, gendered, racialized ideals, providing the upper-class white male to escape from the “feminized” city. As a national movement “conservation,” justified the displacement of Native Americans, subsistence farmers, and squatters,¹² to provide a purified escape that reflected ideals of social hygiene.¹³ “Wilderness parks were a response to a perceived crisis of masculinity at the turn of the century; the appeal of the aesthetics of a sublime, mountaintop transcendence could be appealing (or

¹⁰ W. M. Adams, *Green Development: Environment and Sustainability in a Developing World* (Routledge: New York, 2009), 116.

¹¹ Kim Q. Hall, “Crippling Sustainability, Realising Food Justice,” in *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, eds. Sarah Jaquette Ray and Jay Sibara (Lincoln: University of Nebraska Press, 2017), 423.

¹² Mark Spence, *Dispossessing the Wilderness: Indian Removal and the Making of the National Parks*. (New York: Oxford University Press, 1999); Karl Jacoby, *Crimes against Nature: Squatters, Poachers, Thieves and the Hidden History of American Conservation* (Berkeley: University of California Press, 2001).

¹³ Jake Kosek, “Purity and Pollution: Racial Degradation and Environmental Anxieties,” in *Liberation Ecologies: Environment, Development, Social Movements*, eds. M. Peet and R. Watts (New York: Routledge, 2004); Bruce Braun “On the Raggedy Edge of Risk: Articulations of Race and Nature after Biology,” in *Race, Nature, and the Politics of Difference*, eds. D. Moore, J. Kosek, and A. Pandian (Durham, NC: Duke University Press, 2003).

accessible) to men only in such a context.”¹⁴ The enjoyment and participation in normative conceptions of “nature” was premised on exclusivity.

Sarah Jaquette Ray argues that this ethos still pervades much of today’s environmentalism and, further, has provided a blueprint for a specific type of body that is supposed to engage in the outdoors. “Adventure culture’s investments are not just racial, gender, elitist, or imperialist; they fundamentally hinge on the fit body.”¹⁵ Further, this fit body is supposed to engage with nature in an unmediated way, rejecting the technologies that enable mobility in an otherwise disabled body. Perhaps the most blatant example of this is found in Edward Abbey’s *Desert Solitaire*, where he exhorts, “I entreat you, get out of those motorized wheelchairs, get off your foam rubber backsides, stand up straight ... like human beings! and walk-walk-WALK upon our sweet and blessed land.”¹⁶ Kafer documents how this history has influenced park planning and accessibility, and the way in which disabled hikers have pushed back against assumptions that their wheelchairs would cause more damage to public trails than an able-bodied hiker.¹⁷

Ray writes that “even if the myth of an inaccessible wilderness underpins adventure culture, there is no reason that environmentalism, as an activist and theoretical set of ethical imperatives, must share this attachment to the wilderness myth.”¹⁸ Environmentalism, and

¹⁴ Sarah Jaquette Ray, “Risking Bodies in the Wild: The ‘Corporeal Unconscious’ of American Adventure Culture,” in *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, eds. Sarah Jaquette Ray and Jay Sibara (Lincoln: University of Nebraska Press, 2017), 31.

¹⁵ *Ibid.*, 33.

¹⁶ Edward Abbey, *Desert Solitaire: A Season in the Wilderness*, (New York: Touchstone: 1990), 233.

¹⁷ Kafer, *Feminist Queer Crip*, 136-140.

¹⁸ Ray, “Risking Bodies,” 33.

even the more intersectional environmental justice movement, fail to sufficiently address ableism. Valerie Ann Johnson writes that the environmental justice movement typically addresses disparities across race, ethnicity, and socioeconomic status, but doesn't consider gender, sexuality, and disability.¹⁹ Echoing some of the concerns of Taylor and Clare, Johnson asks, "When [environmental] harm occurs, do the people harmed become disabled in a way that renders them less capable of active participation in the movement work?"²⁰ This question might be answered with a "yes," but such a "yes" is intended to reflect negatively on the movements that fail to address disability in meaningful ways and include disabled activists.

Often, the only "appropriate" way for disabled people to engage with wilderness, in the eyes of the general public and media, is through the "supercrip" narrative.²¹ This narrative is one where a disabled person completes an impressive feat, and this story is then used to shame other people, both abled and disabled, for not meeting these standards. Or, in a double bind, the societal expectations for disabled people are set so low that any level of achievement is deemed notable and inspiring. Supercrip stories, such as that of Erik Weihenmayer, the first blind person to climb Mount Everest, glorify willpower and independence in ways that argue that a supercrip isn't really disabled. Disabled people are often expected to be either invisible or extraordinary, positions that fail to offer full access.

¹⁹ Valerie Ann Johnson, "Bringing Together Feminist Disability Studies and Environmental Justice," in *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, eds. Sarah Jaquette Ray and Jay Sibara (Lincoln: University of Nebraska Press, 2017).

²⁰ Ibid, 85.

²¹ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997).

This is not simply a failure of inclusion. I contend that disabled people are situated to provide valuable knowledge in the “arts of living on a damaged planet.”²² For example, those with environmental and chemical sensitivities are familiar with the skills to mitigate the effects of inhaling wildfire smoke.²³ Yet, these skills alone are not enough to save disabled people in the face of increased environment destruction. Disabled people are often disproportionately impacted by climate change and natural disasters.²⁴ In particular, this issue intersects with race and class, and requires multi-issue solidarity to address. Disabled people are both more likely to be exposed to environmental disaster and are more vulnerable to the effects of these disasters when they do occur.²⁵

Given these shortcomings in mainstream environmental movements, I suggest it is necessary to change how we engage with the environment and environmental politics to better consider the relevance of disability, without positioning disability as wholly undesirable. Not all disabled people see themselves as in need of cure. Cure is complex. Some disabled people may seek cure; others may spurn it. Some may want a cure for one part of their bodymind and not another. In this complex web, Eli Clare turns to the concept of ecological restoration:

²² Anna Lowenhaupt Tsing, Heather Anne Swanson, Elaine Gan, and Nils Bubandt, eds. *Arts of Living on a Damaged Planet: Ghosts and Monsters of the Anthropocene* (Minneapolis: University of Minnesota Press, 2017).

²³ Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver, BC: Arsenal Pulp Press, 2018), 40.

²⁴ Patty Berne and Vanessa Raditz, “To Survive Climate Catastrophe, Look to Queer and Disabled Folks,” *Truthout*, January 4, 2020, <https://truthout.org/articles/to-survive-climate-catastrophe-look-to-queer-and-disabled-folks/>.

²⁵ Catherine Jampel, “Intersections of Disability Justice, Racial Justice and Environmental Justice,” *Environmental Sociology* 1, no. 4 (2018).

I feel my grief and rage over environmental losses as small as the disappearance of a single peeper pond and as big as the widespread poisoning of the plant's groundwater. I think about how we might bear witness to body-mind loss while also loving ourselves just as we are right now. I begin to understand restoration-both of ecosystems and of health-as one particular relationship between the past, present, and future.²⁶

Such a restoration involves challenging our social categories of natural and normal, seeing the interrelations of bodies and nature. This challenges us to consider the ways in which we create "others," both among people and between us and our environment.

Disability studies scholars have long argued about the importance of the environment to understanding what constitutes disability. The social model of disability, proposed as an alternative to the medical model, suggests that people experience disability as a result of being in an environment that fails to meet their needs.²⁷ Commonly used examples of the social model, such as a person being disabled as a result of a lack of elevators or curb cuts focus on the built environment. As Alison Kafer notes, there has been relatively little scholarship on the effects of the natural environment on disability, or vice-versa.²⁸

Rosemarie Garland-Thomson explains, "Disability studies reminds us that all bodies are shaped by their environments from the moment of conception. We transform constantly

²⁶ Clare, *Brilliant Imperfection*, 60.

²⁷ Michael Oliver, Bob Sapey, and Pam Thomas, *Social Work with Disabled People*, (Basingstoke, UK: Palgrave Macmillan, 1983); Michael Oliver, "The Social Model of Disability: Thirty Years On," *Disability & Society* 28, no. 7 (2013).

²⁸ Kafer, *Feminist Queer Crip*, 129.

in response to our surrounds and register history on our bodies. The changes that occur when body encounters world are what we call disability.”²⁹ Garland-Thomson’s understanding of disability applies well to disability that is a result of environmental harm. Often, disability studies scholars overlook disability acquired later in life, which can more acutely reflect multiple modes of violence.

Disability justice founders write about the intersections of environmental harm and disability. They trace the multiple ways in which people have suffered environmental illness and injury as a result of industrial capitalism. “The deluge of chemicals in bodies and ecosystems may disrupt our cellular signaling, cause our nerves to sear in pain, but their reality and the resounding reality of their harm orient us to the actions we are being called upon to take.”³⁰ Disability justice requires being attentive to these bodily realities, as well as a re-focusing on the broader conditions that caused them.

What then, are the bodily changes that result from being in the Appalachian environment? Many of our environmental movements engage with disability in some way. For example, in Minden, West Virginia, an old coal mining town, residents disproportionately experience cancer as a result of the land being poisoned with toxic chemicals disposed in an old mine site.³¹ In Martin County, Kentucky, residents faced

²⁹ Rosemarie Garland-Thomson, “Disability and Representation,” *PMLA* 120, no. 2 (2005): 524.

³⁰ *Sins Invalid, Skin, Tooth, and Bone: The Basis of the Movement is Our People*, 2nd ed. (San Francisco, CA: Dancers Group, 2019), 100.

³¹ Natalie Baptiste, “This Town is So Toxic, They Want it Wiped off the Map,” *Mother Jones*, January 8, 2018, <https://www.motherjones.com/environment/2018/01/this-town-is-so-toxic-they-want-it-wiped-off-the-map/>.

decades of unsafe drinking water, and now many struggle to pay their water bills.³² A recent spike in black lung cases in the region has also brought miners together to help each other with disability benefits paperwork.³³ These issues fall outside the boundaries of what some would consider disability issues, a category that might be more likely to evoke those with congenital disabilities than disabilities acquired from living in damaged landscapes. Such cases emphasize that disability is not an individual condition but co-exists in relation to the environment.

Such cases contest a convenient identity-based framework for disability. Indeed, many Appalachian environmental movements ultimately argue against disability. In the case of mining, how are disabled miners used to argue against black lung? The argument here is not that we shouldn't fight against extraction and exploitation, but that we must think more carefully about how we use disabled bodies to further such arguments, and how these arguments leverage disability stigma. An environmental politics recognizes this often unconscious ableism and seeks to address the shortcomings in mainstream sustainable development.

Ecological disablement provides a way to understand disability in relation to Appalachian environmental harm. Through this framework, disability is not an individualized problem, but spreads trans-corporeally through landscapes. If, the environment is

³² Sydney Boyles, "First These Kentuckians Couldn't Drink the Water. Now they Can't Afford It," *NPR*, October 31, 2019, <https://www.npr.org/2019/10/31/772677717/first-these-kentuckians-couldnt-drink-the-water-now-they-can-t-afford-it>.

³³ Carrie Arnold, "A Scourge Returns: Black Lung in Appalachia," *Environmental Health Perspectives* 124, no. 1 (2016).

inextricably connected to the human, then movements for environmental justice need to contend with these assemblages of disability, and the impacts and insights of disabled people on environmental justice. Without considering disability, attempts to save the planet for everybody actually end up harming disabled people.³⁴

Appalachian naturecultures are connected to transnational flows of toxins, especially through extractive industries. Toxins become a mark of stigmatized, essentially disabled, people and communities. Mel Chen reminds us that toxins, both literal and metaphorical, can be one way in which communities become seen as queer, a perspective that connects the environmental impacts in Appalachia with narratives of stigma and othering.

³⁴ Imani Barbarin, "Climate Darwinism Makes Disabled People Expendable," *Forbes*, November 2, 2019, <https://www.forbes.com/sites/imanibarbarin/2019/11/02/climate-darwinism-makes-disabled-people-expendable/>.

Crip/queer Appalachia

Attitudes towards one's disability can be complex, especially in areas where disability is a result of violence or destruction. Views of disability are also complicated when disability is seen as endemic to a population, as it has in Appalachia. While Disability Studies scholar Tobin Siebers notes that many disabled people do not see their disability as a "flaw" or defect," are comfortable with who they are, and opt not to seek a cure, they may not necessarily welcome further disablement.¹ Some disabled people may come to claim "crip" identity – a radical repositioning of disability as a form of pride. Crip can be understood alongside queer as a way of challenging social norms about what a good body and mind might look like. This is especially salient in Appalachia, a region whose othering has been furthered through the othering of its environment and those who live in it.²

How might these forces of othering contribute to productive interdisciplinary conversations that further our understandings of disability and work to counter ableism towards the region and its inhabitants? The academic disciplines that have the most at stake in this project are Appalachian Studies, Queer Studies, and Disability Studies, which have some shared concerns. As stef shuster contends, both Queer Studies and Appalachian Studies are concerned with questions of identity and belonging.³ Carrie Sandahl argues that for the interrelation of disability and queer studies, as fields that both address deviant identities.⁴ In

¹ Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008), 4.

² Rebecca R. Scott, *Removing Mountains: Extracting Nature and Identity in the Appalachian Coalfields* (Minneapolis: University of Minnesota Press, 2010).

³ stef m. schuster, "Quaring the Queer in Appalachia," *Appalachian Journal* 46, no. 1-2 (2018).

⁴ Carrie Sandahl, "Queering The Crip Or Crippling The Queer? Intersections of Queer and Crip Identities in Solo Autobiographical Performance," *GLQ: A Journal of Lesbian and Gay Studies* 9 no. 1-2 (2003): 25-56.

this chapter, I attempt to triangulate from these arguments and suggest how a link between disability studies and Appalachian studies might broaden queer scholarship. Recognizing the importance of place and environment to Appalachia, I make my argument through queer assemblages of people and environment.

The phrasing of crip/queer draws attention to reclaimed radical identities that have the power to transform social relationships.⁵ Like queer, crip is a reclaimed pejorative that has come to be used as a celebration of deviant identity. Crip “is a term which has much currency in disability activism and culture but still might seem harsh to those outside those communities.”⁶ Crip primarily entered the academic lexicon of disability studies through Carrie Sandahl’s article “Queering the Crip Or Crippling the Queer?”,⁷ Robert McRuer’s *Crip Theory*,⁸ and Alison Kafer’s *Feminist Queer Crip*.⁹ These keystone texts make intellectual connections between disability and queer studies and think about the ways in which intersectionality and solidarity can be performed, both between academic disciplines and individual identities.

My turn to the crip/queer has been informed by the rise of Queer Appalachia (@QueerAppalachia) as a social media and cultural movement, highlighting the often rural nature of Appalachian queerness. Queer Appalachian spaces can exist through academic texts

⁵ My understanding of “crip/queer” and its implications has been influenced by Sami Schalk. See Sami Schalk, “Coming to Claim Crip: Disidentification with/in Disability Studies,” *Disability Studies Quarterly*, 33 no. 2 (2013).

⁶ Kafer, *Feminist Queer Crip*, 15.

⁷ Sandahl, “Queering The Crip.”

⁸ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*, (New York: New York University Press, 2006).

⁹ Kafer, *Feminist Queer Crip*.

but also reach outside of boundaries to include popular culture, as well as art installations and media projects. Queer Appalachia has also published two volumes of their zine, *Electric Dirt*.¹⁰ These efforts are not only about “queers,” they also work “to queer” how Appalachia is understood and engaged with in new and diverse ways in ways that reach beyond a queer-identified community.

Disability issues crop up throughout *Electric Dirt*. Shoog McDaniel writes about the shame of being disabled and superfat, and the accompanying frequent exclusion from queer spaces.¹¹ Another, anonymous contributor writes about how having an invisible disability, and how their family and community sees them as a burden.¹² Both these essays grapple with ableism, both internal and external – but neither asks for a cure for their disability, instead focusing on the societal barriers that challenge disabled existence, especially in the rural Appalachian South.

Sandahl describes crip as a “fluid and ever-changing” term which “expanded to include not only those with physical impairments but those with sensory or mental impairments as well.”¹³ However, for some, crip is still too tightly associated with those who are physically disabled – activists who have claimed that their bodies may be impaired but

¹⁰ Queer Appalachia, ed., *Electric Dirt: A Celebration of Queer Voices and Identities in Appalachia and the South*, vol. 1 (Bluefield, WV: Queer Appalachia, 2017); Brontez Purnell, ed., *Electric Dirt: A Celebration of Queer Voices and Identities from Appalachia and the South*, vol. 2 (Bluefield, WV: Queer Appalachia, Forthcoming Spring 2020.)

¹¹ @Shooglet, in *Electric Dirt*, vol. 1. 152-153.

¹² Anonymous, in *Electric Dirt*, vol. 1. 154-160.

¹³ Sandahl, “Queering the Crip,” 27.

their brains work just fine – a positioning that creates a disability hierarchy and dismisses the important contributions by those with cognitive disabilities. Because of this, autistic rhetorician Melanie Yergeau turns to the “neuroqueer,” recognizing the inherent queerness of those with all types of disabilities.¹⁴ Drawing on these theories shows how disability has been positioned alongside queerness.

Crip is not a perfect parallel for queer, though it often does similar work. Disability theorist McRuer describes crip as having:

a similar contestatory relationship to disability studies and identity that queer theory has to LGBT studies and identity, crip theory does not—perhaps paradoxically—seek to dematerialize disability identity.¹⁵

Crip theory does not discard disability identity, though it does destabilize it through rethinking what might otherwise be thought of as discrete and natural categories. In addressing the relevance of the crip/queer to Appalachia, it is necessary to address the centrality of place and environment in Appalachian Studies. Appalachia has long been constructed as a place apart from the rest America. William Schumann notes that “Appalachian place-making is often dominated by powerful economic and political actors, such as energy companies and elected officials, who define resource exploitation as a way of ensuring regional economic development and the national security of the United States.”¹⁶

¹⁴ Melanie Yergeau, *Authoring Autism: On Rhetoric and Neurological Queerness* (Durham, NC: Duke University Press, 2018).

¹⁵ McRuer, *Crip Theory*, 35.

¹⁶ William Schumann, “Introduction,” in *Appalachia Revisited: New Perspectives on Place, Tradition, and Progress*, eds. William Schumann and Rebecca Adkins Fletcher (Lexington: University of Kentucky, 2016), 9.

Likewise, there have been parallel strands of place making that focus on resistance to extractive industries and progressive social movements. Thus, “place-making in Appalachia operates on the principle of marking difference between one reading of human-environmental relations and all others.”¹⁷ As Steven Fisher and Barbara Ellen Smith argue, “place” has the potential to contribute to “new forms of progressive organizing.”¹⁸ Projects such as Queer Appalachia and Rachel Garringer’s oral history project, Country Queers,¹⁹ are deeply rooted in this understanding of place’s transformative potential.

Both the Country Queers and Queer Appalachia projects draw heavily upon notions of place and local culture to articulate queer identities. Ethan, a Kentuckian interviewed for Garringer’s Country Queers projects speaks to the connection of Appalachian identity and place:

Appalachians have an extreme sense of family and a sense of place, those are very extreme where I come from, I mean those are very obvious. Every, you know, family is not just your blood kin, it’s everybody that you grew up with, everybody that you know. And then sense of place is you know where you’re from and a sense of pride around that.²⁰

¹⁷ Ibid.

¹⁸ Stephen I. Fisher and Barbara Ellen Smith, “Introduction,” in *Transforming Places: Lessons from Appalachia*, ed. Stephen I. Fisher and Barbara Ellen Smith (Urbana: University of Illinois Press, 2012), 6.

¹⁹ Rachel Garringer, “‘Well, We’re Fabulous and We’re Appalachians, So We’re Fabulachians:’ Country Queers in Central Appalachia,” *Southern Culture* 23, no. 1 (2017) and <https://countryqueers.com/>.

²⁰ Ethan Hamblin, quoted in Garringer, “Well, We’re Fabulous and We’re Appalachians,” 85.

Ethan's story documents the close ties, both with blood relatives and chosen family, that, in his opinion, exemplify country life. This writes against the notion that Appalachia is not a welcoming place, as Ivy, another Country Queer's interviewee, expresses:

No. I don't [think that being from the country made it more difficult to come out]. Because I know people who grew up in cities, who had a harder time than me, you know? And in some ways, I think growing up where I did made it easier, and made it better, because people really knew who I was, and knew where I was coming from.²¹

These quotes challenge mainstream ideas of who Appalachians are and unsettle dynamics of the rural as an unwelcoming place, rethinking the ways in which otherness is understood.

The study of queer ecologies challenges normative conceptions of nature as a space separate from human culture and considers nature spaces to have been constructed historically around ideas of cisheteronormativity.²² Queering nature and ecology allows for new ways of thinking through human and non-human relationships. While "queer ecology" draws upon the relations of queer-identified people and the natural world,²³ we can consider the term more broadly in the sense of unusual alliances and places that defy easy categorization – for example, Appalachia.

Appalachia can be understood as a queer place, a place that has been set apart as America's other. As Eller describes: "Appalachia has become a Janus-faced "other" ... [and]

²¹ Ivy Brashier, quoted in Garringer, "Well, We're Fabulous and We're Appalachians," 85.

²² Catriona Mortimer-Sandilands and Bruce Erickson, *Queer Ecologies: Sex, Nature, Politics, Desire* (Bloomington: Indiana University Press, 2010).

²³ Ibid.

represented a geographic barrier on the frontier, “a strange land inhabited by a peculiar people”—a people who were at once quaint and romantic and yet a burden to American success.”²⁴ Appalachian people have long been labelled with deviant identities. One of the more prominent reclaimed labels is that of the hillbilly.²⁵ Hillbilly is another stigmatized identity that some Appalachians have taken pride in. Some queer Appalachians even claim a derivative: “queerbilly.”²⁶

I turn to the phrase “assemblage” to describe the complex relationships that form on multiple scales between organisms of various types. Anna Tsing writes that:

Ecologists turned to assemblages to get around the sometimes fixed and bounded connotations of ecological “community.” ... Assemblages are open-ended gatherings. They allow us to ask about communal effects without assuming them. They show us potential histories in the making. ... If history without progress is indeterminate and multidirectional, might assemblages show us its possibilities?²⁷

Assemblages allow for a relational understanding that recognizes how our social world is enacted by both human and non-human actors. Understanding this complexity lets us further think about how the assemblage that makes up the environmental movement can be crippled

²⁴ Ronald Eller, “Foreword,” in *Back Talk from Appalachia: Confronting Stereotypes*, eds. Dwight B. Billings, Gurney Norman, and Katherine Ledford (Lexington: University Press of Kentucky, 1999), ix-x.

²⁵ Jerry Williamson, *Hillbillyland: What the Movies Did to the Mountains and What the Mountains Did to the Movies* (Chapel Hill: University of North Carolina Press, 1995); Anthony Harkins, *Hillbilly: A Cultural History of an American Icon* (New York, Oxford University Press, 2004); *Hillbilly*, directed by Ashley York and Sarah Rubin (Warren, NJ: Passion River Films, 2018).

²⁶ Mathias J. Detamore, “Queer Appalachia: Toward Geographies of Possibility,” (Ph.D. Thesis, University of Kentucky, 2010).

²⁷ Anna Lowenhaupt Tsing, *The Mushroom at the End of the World* (Princeton: Princeton University Press, 2015), 22-23.

and queered. Assemblages move beyond intersectionality and a focus on identity to think about multiple forces that destabilized fixed categories and identities.

I make this argument on both a broad scale and think of the specific ways in which it can relate and build from social movements in Appalachia, most notably Queer Appalachia. I use Queer Appalachia to think with because it has shown that progressive social ideals are inherent in populations that might otherwise be typecast as backward, and it challenges biases in both queer studies and Appalachian studies, an unsettling of norms I find productive in developing crip projects. By bringing crip and queer together theoretically, I think about how our attempts to queer Appalachia need to also include understandings of disability.

Environmental issues can also be disability issues, which can also be race and class issues. If Appalachia perhaps is a queer place, these issues are also implicated in queer movements. McDaniel provides some ways this might look like for radical queer organizing:

List accessibility on your events. Ask your friends about what they need help with and try to make time to help out those folks who need a little more. Plan trips that are specifically accessible and fun for your friends who might not get invited much. Talk to your friends who say or do ablest [sic] things. Don't talk about your diet with us; we don't care.²⁸

Building anti-ableist practices into community organizing creates a meaningful way to address disability histories in Appalachia. Disability has been part of negative stereotypes

²⁸ @Shooglet, in *Electric Dirt*, vol. 1, 153.

about Appalachia, but it needs to be addressed as a very real part of our communities and movements in ways that challenge ableism.

Crip/queer is not meant to simply refer to the overlap between disabled and LGBTQ+ populations, of which there is a significant overlap,²⁹ but to think about the projects of solidarity and mutual support such a phrasing entails. The solidarity between crip/queer theories can contribute to building on Appalachian social movements in ways that continue queer projects and address the lack of critical attention to disability. David Harvey has argued that place-based activism can be important for building momentum on everyday issues, yet they run the risk of becoming ineffective and exclusionary if they fail to form solidarities with allies and broader struggles.³⁰ Drawing on Harvey's work, Jennifer Rice and Brian Burke studied environmental justice in western North Carolina as a form of situated solidarities, which they define as "potential connections between various social movements that are forged in place to acknowledge and honor the diversity of people and ways in which we come to enact various forms of resistance, while also connecting beyond place to recognize the wider causes of our oppressions and marginalizations through mutual respect."³¹

Bringing disability and queer studies in conversation with Appalachian studies is a form of solidarity. It is also necessary to note that these fields, while they all take an

²⁹ Movement Advancement Project, *LGBT People With Disabilities* (July 2019), <http://www.lgbtmap.org/lgbt-people-disabilities>.

³⁰ David Harvey, *Justice, Nature, and the Geography of Difference* (Malden, MA: Blackwell, 1996).

³¹ Jennifer L. Rice and Brian J. Burke, "Building More Inclusive Solidarities for Socio-Environmental Change: Lessons in Resistance from Southern Appalachia," *Antipode* 50 (2018): 8.

approach to studying minorities and peripheries, can fail at being inclusive, most notably in terms of addressing people of color.³² While these fields have all acknowledged this shortcoming to some extent, it is important to note that enacting diversity in certain ways does not excuse other failures. Any new alliance should work to learn from these past failures and recognize the complexities of race among other aspects of identity.

Disability justice goes beyond notions of rights and seeks to center the voices of those who are marginalized in traditional disability rights spaces, such as queer people, indigenous people, and people of color. Disability justice recognizes that rights are granted by a settler-colonialist cisheteropatriarchal state that many are unable to access. The disability justice approach is an intersectional one and it argues for leadership by those most impacted, and thus is helpful in thinking intersectionally about those who are marginalized by ability, gender, sexuality, class, and geography.

³² E.g. Chris Bell, "Introducing White Disability Studies: A Modest Proposal," in *The Disability Studies Reader*, 2nd ed, ed. Lennard J. Davis (New York: Routledge, 2006).

Appalachian Care Networks

A large part of building disability justice is through community care. Disability justice posits that care, an honest grappling with the needs of disabled communities and how these needs could be met in community, is essential to disability justice.¹ This demands an attention to how disabled people build and adapt spaces in order to meet their needs and support others. This is what might be termed “radical care,” one that draws on histories of community grassroots activism and negates neoliberal regimens of self-care.² Appalachia has strong histories of mutual aid and localized practices of care.

To think about the ways in which disabled people might create care-focused spaces for themselves, I visited my local senior center, referred to throughout this piece as the “Project on Aging.” This space exists in a grey area between a medical institution and community space. While it doesn’t provide medical treatment, programming routinely engages with health and wellness ideals through prevention services, health screenings, and promoting activity –through physical movement, social connectivity, and pursuit of interests.

Stephen Katz discusses how activity has become central to understanding aging and health promotion.³ Activity has been a key part of aging frameworks since the 1940s, and as Katz argues, has come to represent a disciplining of the older body as an aspect of neoliberalism. Katz’ framework suggests that the Project on Aging may be a biopolitical one

¹ Piepzna-Samarasinha, *Care Work*.

² Hi‘ilei Julia Kawehipuaakahaopulani Hobart and Tamara Kneese, “Radical Care: Survival Strategies for Uncertain Times,” *Social Text* 38, no. 1 (2020).

³ Stephen Katz, “Busy Bodies: Activity, Aging, and the Management of Everyday Life,” *Journal of Aging Studies* 14 no. 2 (2000).

of managing bodies and society. However, disability theorists have long argued that disability exists outside of medicalization. I claim that the Project on Aging exists both as a space for the management of older bodies, as well as a space of what Cassandra Hartblay terms “disability expertise.”⁴ Through Hartblay’s ideas of disability expertise and disability anthropology, I examine the ways in which Project on Aging participants create social worlds around disability and impairment.

“Disability anthropology,” as described by Hartblay, has two defining features: engaging trans-disciplinarily with critical disability studies, and, second, utilizing the point of view of disabled people themselves. “Disability anthropology asks what the category of disability does in the world, and in particular, in local disability worlds.”⁵ Thinking about local disability worlds also connects to the framework of “aging in place,” which can simply refer to remaining in one’s home while aging, but can also theoretically refer to the ways in which place impacts the aging experience.⁶

While the Project on Aging does not claim to be “Appalachian,” it inevitably engages with local cultures and traditions. The sewing group builds on skills some members have had since childhood. While quilting and weaving aren’t exclusively Appalachian, they provide a culturally responsive way of building community. In these spaces, participants also share their experiences of aging in this particular place. Some of the participants have lived in the

⁴ Cassandra Hartblay, “Disability Expertise: Claiming Disability Anthropology,” *Current Anthropology* 61, supplement 21 (2020).

⁵ Hartblay, “Disability Expertise,” S34.

⁶ Jana Kopelent Rehak, “Aging in Place: Changing Socio-ecology and the Power of Kinship on Smith Island, Maryland,” *Anthropology & Aging* 40, no. 1 (2019).

area their entire lives and share stories of their childhoods and the development they've seen in the area over the years.

The lobby of the Project on Aging is an unsettling mix of hominess and institutionality. A reception desk, low ceiling, and florescent lights contrast with the mix of rocking chairs, books, and board games that would seem cozy and welcoming if located somewhere other than in the county human services complex. Behind the reception desk is the director's office, filled with stacks of papers. The other offices are clustered together around an interior hallway and house workers who arrange programming, meal delivery, and in-home care. The exterior hallway is where I normally wander on my visits, walking past artwork of various styles and bulletin boards overloaded with fliers, deciding which classroom I will venture into, nervously introducing myself as a university student, drawing on either my Appalachian Studies background [can you tell me about what it was like growing up around here?] or as someone taking classes in healthcare and aging [what challenges have you faced getting old?].

Depending on the day of the week, the activity rooms around the edge of the buildings will be purposed in different ways. There's a room for crafts, a room for hanging out and playing games, and the larger multipurpose/cafeteria room, with tables set up in a "U"-shape. Most of the rooms have large windows overlooking the parking lot and the drop down to road below. The exception is the exercise room, windowless, in a more interior location, packed with stationary bikes and other equipment. During my initial tour, the director told me that people liked to hang out in here, but I found it mostly unused. This collection of rooms could be used for any sort of office or human services purpose. The generic nature of a space to serve a particular population surprised me.

The Project on Aging provides a physical space to congregate, as well as coordinating other services and helping older adults navigate resources such as Medicare. Those who cannot come for lunch can sign-up to receive home delivered meals. In-home aide services may also be available in coordination with outside agencies to help prevent institutionalization. These programs reach out into the community and enhance those offered by the senior center to serve a wider range of adults and support community care. The senior center staff would claim that what they do greatly increases the wellbeing of older adults through offering engaging activities, a chance to socialize, and healthy food.

Though I do not disagree that these are valuable interventions that most likely have great value in the lives of those who participate at the senior center, I wish to complicate the use of these generally accepted biomedical ways to increase health and wellness and think about the center as a disability-focused space that allows for multiple aspects of care and resistance to ableism. Care is a human need, but it comes with its fair share of baggage. Disabled people may be subject to care that is abusive, whereas those expected to take caregiving roles are often lower class, women, and people of color. When formalized through the medical complex, caregiving often emphasizes the precarity and scarcity of capitalism, providing inadequate care, such as the in-home aide care that can be coordinated for roughly four hours a week through the Project on Aging.

My visits to the Project on Aging typically involved sitting in on a morning exercise class and then participating in bingo games until lunchtime. Most people who come to the Project on Aging followed a similar pattern, coming in the morning for an activity or informal socializing, and leaving after lunch. Those who don't drive are reliant on public transportation – van drop off and pick-ups follow this schedule. People tend to hang out in

specific groups. For example, there's 5 or so people that exercise regularly, another group reliably plays bridge every time I visit. There's also groups of talented artists and a weaving class. Around holidays, there will be special programming – such as a summer field day or a tree decorating party. Every month, there are also outings to local attractions. The programming in general follows a framework that encourages active aging.

I entered this space wondering about care networks, and the ways in which disabled people make spaces for themselves. I am cautious of categorizing older people as disabled, in part because this confirms ageism against older people. Yet, living in an area without a center for independent living or other community group for disabled people, I was fortunate to find the Project on Aging to be a location that welcomed me as a researcher. Through a critical disability studies methodology, one can examine older people as categorically “disabled,” through societal forces and marginalization, not necessarily through status of health or impairments – though many participants would also meet medical/legal criteria for a disability.

This shifts analysis towards the forces that produce the nexus of ability/disability and marginalize particular types of ability. In the case of my project, disability was never explicitly mentioned as such, though it was a lived reality for many of the people with whom I spent time. The majority of people at the Project on Aging are experiencing disability that comes with aging, as opposed to aging with a disability. As one of my interviewees told me, “aging ain't all it's cracked up to be.” This can be interpreted as both the decline of the aging body and in the cultural devaluation of old age.

My focus is on the power dynamics that marginalize the sorts of bodyminds I met at the senior center, and the ways in which these dynamics are resisted through carving out a

place that resituates aging bodyminds as an acceptable way of being in the world. Creating a disability/aging focused space makes room for new potentialities. In my fieldwork, I listened for openings for new connections, that (likely inadvertently) defied the tropes of lives devoid of potential, or whose only potential is cast as negative. Instead, participants at the Project on Aging created opportunities to share these experiences in ways that did not deny their lived realities, but brought them to share with other people, opening up opportunities for collaboration and mutual understanding.

I entered the Project on Aging wondering if it had the potential to be more than a site for productive aging. These potentialities opened up the most when the script was flipped from older adults as being recipients of services to those who defined what successful aging looks like to them. Part of disability expertise is the management of networks of power. Hartblay notes that “disability expertise is not ‘resistance’ in the sense of activist agitation against Power with a capital P, but rather the emergent relation enactment of configurations of diffuse power.”⁷ In the case of the Project on Aging, I contend that participants enact relationships that contest a purely biomedical view of aging to integrate it with localized methods of support.

Rather than being activist actions, they are what Arseli Dokumaci calls “microactivist affordances”—a term to describe micro (and often ephemeral) acts of world building, with which disabled people literally “make up,” and at the same time “make up for,” whatever affordance fails to readily materialize in their environments.⁸ More specifically, what I

⁷ Hartblay, “Disability Expertise,” S34.

⁸ Arseli Dokumaci, “Vital Affordances, Occupying Niches: An Ecological Approach to Disability and Performance,” *RiDE: Journal of Applied Theatre and Performance* 22, no. 3 (2017).

observed at the Project on Aging was what Dokumaci calls “people as affordances,” the idea “that people can enable the emergence of, or directly become, affordances for one another, especially when the affordances that their coming-together might create do not and could not otherwise exist within the niche they share.”⁹

In my interviews, people often stressed their independence, even though they relied on each other for support. Among the senior citizens I spoke with, independence happens alongside interdependence, but independence is what is prized more. One day during a visit, I sit at a table in the lunchroom across from Anne and start asking her questions about her social networks at the senior center. She tells me she comes to the senior center three times a week and leads an exercise class each morning that she is there. Her sister also comes to the senior center. Anne tells me that she doesn’t know everyone who comes, but that she knows the people who sit at her table, table number three, pretty well. I think about being back in grade school, where the table you sat at had important social implications and wonder about the unspoken social navigation of the seating arrangements.

During the time Anne and I are talking, I flash back to school once again, as someone from table four passes a handwritten note down to someone seated at table two. These small, yet meaningful connections create an atmosphere of interdependence. However, when I ask Anne if she lives alone [she does], and if she talks to her daughter, who is a nurse, much to get medical advice [she doesn’t – she can take care of herself], Anne’s answers emphasize her independence. She drives herself to the senior center and manages her home and garden on her own, though she admits she doesn’t garden as much as she used to.

⁹ Arseli Dokumaci, “People as Affordances: Building Disability Worlds through Care Intimacy,” *Current Anthropology* 61, supplement 21 (2020): S100.

There is a pride and fierceness in claiming independence here, a response to the ableist notions that position reliance on others as something undesirable. To be seen as reliant on others is negative, but this type of reliance is viewed differently than the social connectedness at the senior center, which is highly valued. Linda Tuhiwai Smith notes that the value of making connections and affirming connectedness as notable among those working with marginalized groups.¹⁰ Attending the senior center creates and strengthens networks, both with childhood friends and newer acquaintances.

This connectedness can be understood through positioning the relationships formed at the Project on Aging through “people as affordances.” The one day I happen to go on a Thursday, I visited a sewing class. I had seen the collection of sewn items for sale in the lobby but hadn’t yet pieced together that these items were created during a class. On this day, five women were working in a smaller classroom. I started up a conversation with one woman, working at a sewing machine, making a padded basket, using rabbit-print fabric in reference to the upcoming Easter holiday. Another woman is assembling an applique rooster for a wall hanging. She calls me over and shows me this sewing case that she made. Through my conversations with the women in the room, I see the ways in which the simple space of a sewing class becomes a place to share and negotiate the aging process. They tell stories about their childhood, deceased family members, illnesses and health challenges, while at the same time telling me how much has changed since their childhood. One woman rattles off all of the mishaps that have happened to her body in the past several months, and then a couple of crafters compare their experiences with vertigo. I can sense a fondness among the women in

¹⁰ Linda Tuhiwai Smith, *Decolonizing Methodologies*, 2nd edition (London: Zed Books, 2012), 149.

the room that goes far beyond a shared enjoyment of crafting. Through shared experiences, along with physical and material support, the Project on Aging participants enact disability expertise and affordances.

One man, “Robert,” arrives early every day. Terse, often sitting alone, he doesn’t strike me as the most outgoing. But when he does speak, he authoritatively connects with increased development, especially related to the university and the lack of opportunity for local businesses to succeed. Someone who grew up in the area and whose cousin also attends regularly, Robert had a sense of tightening potentialities for the place: “If I wanted to go into business, I couldn’t do it because of the zoning regulations,” complaining about the growth of apartments complexes and hotels. Robert periodically shows up with food brought from his church’s food bank. Consisting of primarily overripe produce, pantry staples, and day-old baked goods, he brings in large boxes, and participants can pick out what they would like to take home. In addition to the food prizes from bingo games, participants are able to provide material support for each other outside of the meals organized by the senior center.

One interesting aspect of these actions is that they happened outside of the established framework of the Project on Aging. There was no administrative oversight into whether or not the exercise class followed the prescribed framework, nor did staff keep track of food brought in for donations, or whether bingo players stuck to the rules (and there was debate about what precisely the bingo rules were). Older adults were willing to adjust the services offered to meet their needs, in ways that I argue shows a rebuilding of their environment to create a culture of care that exists within, but autonomously from, the space of county and state governance.

Activities at the Project on Aging also trouble orderly notions of time and space. In being flexible about how the official programming is engaged with, and sometimes even determining when activities happen, by showing up late or making use of the space in ways different from which it was attended. In writing about anthropological approaches to understanding time, Peter Lutz discusses about the different spatial-timings used by homecare workers and how these trouble subjective-objective distinctions.¹¹ This is similar to what Margaret Price terms “crip spacetime,”¹² elaborating on theories of “crip time.”¹³ “Crip time” is used colloquially by some in the disability community to think about the ways in which being disabled entails a flexible approach to time, as well as different ways of experiencing time’s passage or the lifespan. Crip spacetime is not simply a different subjective way of spatial-timings; it is taking a malleable approach to spacetime and reshaping it to best fit the needs of the bodyminds that are present.

I think about how much of aging happens in ways that are pushed out of sight, in institutions of various names. And then I think about the sign hanging over the pool table in the recreation room. It reads: “Pool table reserved for those age 60 and above,” typed simply on white paper. At first this struck me as oddly specific, since the technical minimum age to use any of the senior center’s facilities is sixty, and I didn’t see any reason to think that the pool table would be any different. I wondered if there was a problem with college students

¹¹ Peter A. Lutz, “Surfacing Moves: Spatial-Timings of Senior Home Care,” *Social Analysis: The International Journal of Social and Cultural Practice* 57, no. 1 (2013).

¹² Margaret Price, “The Precarity of Disability/Studies in Academe,” in *Precarious Rhetorics*, eds. Wendy Hesford, Adela Licona, and Christa Teston (Columbus: The Ohio State University Press, 2018).

¹³ Irving K. Zola, “The Language of Disability: Problems of Politics and Practice,” *Australian Disability Review* 1, no. 3 (1988); Carol J. Gill, “A Psychological View of Disability Culture,” *Disability Studies Quarterly* 15 (1995).

sneaking in to play pool here when the bars are too crowded. Now I see the sign as an act of claiming spacetime. We are over sixty. This is ours. Our place to use in our ways.

I present the senior center as a site of redefining what it means to be old in part as an act of prefigurative politics. This is a tricky balancing act, between my wishes for the future and an awareness of the risk of imposing my own desires on others. I look at the senior center and see the potential in among a population that has been assigned a marked lack of potential. Though I doubt Project on Aging participants purposefully plan their actions as speaking back against neoliberal ordering logics. Yet, their actions create a culture of care that shows how disability and impairment necessarily adjust social spaces and how they are engaged with. Even in small, everyday ways, disability generates new ways of being in the world and being with each other.

Conclusion

These chapters take disparate groups of people and show their similarities through a critical disability studies methodology. These examples do not show an emergent disability movement in Appalachia. Rather, they suggest ways in which disability issues connect to social movements that have been important in Appalachia, both past and present. This thesis, and its project of claiming disability is an effort at consciousness raising, coming to identify disability as something that politically matters. Raising disability consciousness often involves moving away from seeing disability as a personal experience and towards a collective political issue.¹ Disability has the potential to bring people together as a social movement, but it also articulates with activist work being done in other areas, including labor, environmental justice, LGBTQ+ issues, and community-building.

According to Marx and McAdam, there are four criteria that should be used to judge social movements: political or economic changes, the development of specific legislation, changes in public opinion, and the formation of new institutions or organizations.² In some cases, the disability rights movement has achieved these; however, in Appalachia, disability issues have been folded into various social movements. In “claiming disability,” I am comfortable examining the intersections, ultimately recognizing that combatting an ableist devaluing of bodies matters more than the claiming of disability identity or pride.

¹ Jane Campbell, *Disability Politics: Understanding Our Past, Changing Our Future* (New York: Routledge, 1996).

² Gary T. Marx and Doug McAdam, *Collective Behaviour and Social Movements* (Englewood Cliffs, NJ: Prentice Hall, 1994).

Taking a broader, critical disability studies approach allows us to see the impacts of disability, even when it is not explicitly named as such. Cases like these are prevalent all over the globe, and a critical disability studies perspective makes connections between movements that might otherwise seem disjointed. I situate these cases in Appalachia along with others throughout the world, following Jasbir Puar's conception of debility. As Puar claims:

At our current political conjuncture, Black Lives Matter, the Palestinian solidarity movement, the protest against the Dakota Access Pipeline to protect sacred grounds and access to water: these are some of the movements that are leading the way to demand livable lives for all. These movements may not represent the most appealing or desired versions of disability pride. But they are movements anchored, in fact, in the lived experiences of debilitation, implicitly contesting the right to maim and imagining multiple futures where bodily capacities and debilities are embraced rather than weaponized.³

None of these movements explicitly consider themselves to be about disability, but they all consist of people who are more prone to disablement in one way or another, especially through state sanctioned violence. Recognizing such movements as related to disability forces us to consider which bodyminds matter and which are routinely exposed to harm.

Bringing disability into our conversations is an important political act that can enhance our conversations of social and environmental justice. A "good future" may not equal the absence of disability – as the biomedical model might suggest – but rather, a reinvention of disability's social significance and cultural possibilities as part of our

³ Puar, *Right to Maim*, xxiv.

understanding of the continued significance of Appalachia. As we ponder questions of what a “just transition” for Appalachia might look like, it is essential that our perspectives be informed by disability.

Disability is a trait that is culturally relevant in Appalachia, though highly stigmatized. It also can provide a starting place for an anti-capitalist politics that challenges normative conceptions of worth and productivity. Stephen Fisher challenges movement building in Appalachia to engage with both local culture and a class-based approach to oppression. He contends that an emphasis on movement building through focusing on culture and tradition should not elide questions of power, privilege, and capital.⁴ By examining what disability has to offer this two-pronged approach, I show why engaging critically with disability has the potential to shape resistances movements in Appalachia and why this should matter to both scholars and activists.

Disability has long been assumed to be a part of Appalachian culture. Perhaps most notably, Kai Erickson considers ability/disability to be one of the defining features of Appalachian people in his study of the Buffalo Creek flood. Erickson located the people of Appalachia “at some vague midpoint between ability and disability.”⁵ Noting the physical strength and endurance it took to persist in an often dangerous landscape, he points out a potential irony in how injury-prone people were, “spending inordinate amounts of time nursing symptoms that in another time and place might have passed unnoticed altogether.”⁶

⁴ Stephen L. Fisher, “Conclusion,” in *Fighting Back in Appalachia: Traditions of Resistance and Change*, ed. Stephen L. Fisher (Philadelphia: Temple University Press, 1993), 317-336.

⁵ Kai T. Erickson, *Everything in Its Path: Destruction of Community in the Buffalo Creek Flood* (New York: Simon and Schuster, 1976), 87.

⁶ *Ibid.*, 88.

This claim is perhaps best interpreted in relation to the intense trauma faced by those in the Buffalo Creek community, an event that encapsulates vulnerability and ecological disablement. If the people of Buffalo Creek were prone to disability, perhaps this was due to extractive industry as much as any innate predisposition.

I do agree that disability has been an integral part of Appalachian culture, though I suggest that it is largely so because of forces that have stigmatized certain elements and created conditions ripe for exploitation, not because of an essential physical reality. The dual images of the mountaineer as rugged and at the same time in need of social uplift, combined with economic and political imbalance have created the conditions for Appalachia to be seen as disabled. In fact, this presumption of disability has perhaps only served to further the actual prevalence of disability through attempts to develop and rehabilitate Appalachia. Where my thinking diverges from early Appalachian Studies scholars, and perhaps many even today, is the assumption that disability is necessarily a negative cultural aspect, what Alison Kafer deems to be an “an ableist failure of imagination.”⁷ Even in today’s world of increased policies of access and inclusion in neoliberal economies, disability remains markedly undesired.⁸ Instead, I contend that the disabled bodymind offers a productive position to consider what Appalachian futures might look like and move towards a more just community for all.

Some might see disability as a cultural lack. However, disabled people have formed rich cultures of their own. Disabled strategies for organizing and building community are

⁷ Kafer, *Feminist Queer Crip*, 4.

⁸ Kelly Fritsch, “Desiring Disability Differently: Neoliberalism, Heterotopic Imagination and Intra-corporeal Reconfigurations,” *Foucault Studies* 19 (2015).

inevitably valuable, especially in times of crisis that call for new ways of coming together. “As disabled people engaged in disability community, activism and scholarship, our collective experiences and histories have taught us that we are effective agents of world-building and -dismantling toward more socially just relations. ... Disabled people are experts and designers of everyday life.”⁹ Not only are disabled people experts of everyday life, disabled people are masters at navigating challenging situations and finding inventive solutions. Including disabled people in community organizing is likely to open up new possibilities and provide valuable insights. Rather than seeing accessibility as a burden or a step of tasks to be completed to ensure compliance, collaborating with disabled people to create accessibility practices will improve access for everyone and should be a key component of any justice-oriented space.

Such an ethos of creativity is apparent in the disability rights movement, as well as less documented daily interactions between disabled people. Protesters at the 1977 sit-ins to authorize section 504 of the Rehabilitation Act, a key piece of disability rights legislation, used their disability expertise to occupy federal buildings all over the country, most notably in San Francisco for 25 days. During this time, wheelchair users who were skilled with mechanics through having to repair their wheelchairs adapted these skills to modify an air conditioner into a refrigerator, and Deaf people used ASL to communicate with supporters on the outside of the building after telephone lines were shut down.¹⁰ This ethos of ingenuity takes place in less dramatic contexts as well, when disabled community members form

⁹ Aimi Hamraie, and Kelly Fritsch, “Crip Technoscience Manifesto,” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (2019): 1.

¹⁰ *Crip Camp*, directed by James Lebrecht and Nicole Newnham (Higher Ground Productions, 2020).

mutual aid groups to complement each other's needs, creatively construct ramps and accessible transportation, and adjust procedures to make sure everyone gets taken care of and no one gets left behind.¹¹

Disabled knowledge is especially important in times of crisis. Even now, as we face the uncertainty of COVID-19, the same tactic of using ASL to communicate used during the 504 sit-ins has provided an alternate way to connect in a time of physical distancing.¹² As society in general becomes wary of the world of pathogens, routine strategies used by homebound and immunocompromised disabled people to keep themselves safe suddenly become mainstream.¹³ At the same time that these strategies from disability culture become more broadly acceptable and celebrated, people with disabilities experience concerns over medical rationing and implicit medical bias that deem disabled lives less valuable and worthy of saving.¹⁴ Disability encourages us to think about alternate ways of being in the world and what potential futures might be possible. In times that are uncertain, it is perhaps easier to see the value that disabled knowledge has to offer our movements, as these are issues that disabled people have already been grappling with.

Recognizing disability as a generative source of knowledge might seem unusual, but I contend that organizing around disabled knowledges and experiences is already happening,

¹¹ Piepzna-Samarasinha, *Care Work*.

¹² Lydia X. Z. Brown, in "Organizing in a Time of Social Distancing: The Wisdom of Disability Justice Organizers," Webinar hosted by JOIN for Justice, April 2, 2020.

¹³ Katie Tastrom, "Our Responses to COVID-19 Must Center Disability Justice," *Truthout*, March 21, 2020, <https://truthout.org/articles/our-responses-to-covid-19-must-center-disability-justice/>.

¹⁴ Elaine Godfrey, "Americans With Disabilities Are Terrified," *The Atlantic*, April 3, 2020, <https://www.theatlantic.com/politics/archive/2020/04/people-disabilities-worry-they-wont-get-treatment/609355/>; Ari Ne'eman, "I Will Not Apologize for my Needs," *The New York Times*, March 23, 2020, <https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html>.

and has happened in the past, as is the case in the black lung movement. Identifying the ways in which disability has play a salient role in Appalachian organizing in throughout history might help us consider the possible futures, as well as consider the more regional ways disability-focused work might look like. Admittedly, the disability justice movement first formed in the California Bay Area and may not seamlessly transfer to other settings. Attention to the localized facets of disability, including histories of disability stigma and stereotypes may help develop a disability consciousness that is responsive to Appalachian culture, without imposing a set of outside values and norms.

Focusing on localized expressions of disability expertise opens up new possibilities for cultural anthropology. Disability expertise offers “a descriptive domain that ethnographers might use to understand and interpret how disabled people enact their personhood and moral agency in diverse cultural settings [and] thus circumvents the ethnographic tendency to focus on suffering, while contributing to broader concerns of transdisciplinary critical disability studies scholarship.”¹⁵ To examine disability culture is to examine ways of worldmaking that can upend conceptions of normalcy.

There has been much debate about whether or not there is such a thing as disability culture. Steven Brown describes a 1991 meeting of the Society for Disability Studies, where a paper on the existence of disability culture sparked heated debate.¹⁶ Since then, disability culture has become slightly more codified, with some shared linguistic practices and rituals.¹⁷

¹⁵ Hartblay, “Disability Expertise,” 34.

¹⁶ Steven E. Brown, *Investigating a Culture of Disability: Final Report* (Washington, D.C.: National Institute on Disability and Rehabilitation Research, 1994).

¹⁷ Crip Ritual Project, <https://cripritual.com/>.

While there are of course drastic differences between sub-groups of disabilities, as well as many people who might be considered disabled but do not identify culturally as such, disabled people have developed shared ways of being in community with one another. A continued investigation into Appalachian disability cultures will help examine specific cultural practices shared by disabled people in Appalachia and show the relevance of disability to “Appalachian culture” more broadly through a critical disability studies methodology.

Disability also supports an anti-capitalist analysis, which is valuable to those working towards a class-based movement, which may be especially relevant in Appalachia as a region often controlled by outside influences and market demands. Disabled bodies inherently challenge a valuation of bodies based on their productive capacities. People with disabilities are also more likely to experience poverty in ways that can build cross-ability class solidarity. Relying on Social Security disability payments forces disabled people to live in poverty,¹⁸ and disabled people are often disenfranchised through employment opportunities, including high rates of unemployment and being paid subminimum wages.¹⁹ It is unsurprising that disability projects provide a trenchant critique of capitalism and its norms of productivity.

Being categorized as ‘disabled,’ however, and the subsequent impoverishment that so many face when struggling to survive no disability benefits, serves another class

¹⁸ David C. Stapleton, Bonnie L. O’Day, Gina A. Livermore, and Andrew J. Imparato, “Dismantling the Poverty Trap: Disability Policy for the Twenty-First Century,” *Milbank Quarterly* 84, no. 4 (2006).

¹⁹ Sarah Kim, “The Truth Of Disability Employment That No One Talks About,” *Forbes*, October 24, 2019, <https://www.forbes.com/sites/sarahkim/2019/10/24/sub-minimum-wages-disability/#5ce71455c22b>.

function: it generates a very realistic fear among workers of becoming disabled ... If workers were provided with a social safety net that adequately protected them through unemployment, sickness, disability, and old age, laborers would gain a stronger position from which to negotiate their conditions of employment.²⁰

Ableism creates conditions where bodies are valued based on their labor, and impaired bodies shore up industries of rehabilitation. Social policies to support disabled people are evaluated based on market value.²¹ In times of crisis, where a greater portion of the population fears becoming disabled and the accompanying material conditions, an anti-ableist approach to organizing takes on new life. Those outside of disability justice circles are not as used to accounting for ableism among the other forms of oppression. Yet, in times of crisis and upheaval, disability justice concerns move “from the margins to the core.”²² It may be that now is precisely the time to consider what disability justice work has to offer.

Through a disability studies methodology that examines the ways in which large portions of the population are systematically disabled under capitalism, one can take an approach rooted in justice, collective liberation, and mutual aid. Practices of disability justice prioritize building practices of care and community.²³ For those interested in such an approach to organizing, disability expertise is especially important. Careful consideration of the potential of the disabled bodymind provides a position from which to build movements.

²⁰ Marta Russell and Ravi Malhotra, “Introduction: Capitalism and the Disability Rights Movement,” in *Capitalism and Disability: Selected Writings by Marta Russell*, ed. Keith Rosenthal, (Chicago, IL: Haymarker, 2019).

²¹ Ibid.

²² Leah Lakshmi Piepzna-Samarasinha, “Every Time is Crip Time Now,” Keynote presented at Society for Disability Studies, April 4, 2020, Zoom.

²³ Piepzna-Samarasinha, *Care Work*.

This work is most powerful when it works beyond the single-issue disability rights framework, which may only seek to incorporate disabled people into pre-existing social structures.

Though the disabled body may be incorporated into practices of neoliberal capitalism through techniques of rights and inclusion, the disability justice framework, which seeks to move beyond a framework of government-granted rights contains valuable lessons for building cross-issue movements in Appalachia. Inclusionist practices recognize a very narrow scope of disability and that they offer no understanding of the “active transformation of life that alternative corporalities disability entail.”²⁴ As disability expertise acknowledges, the disabled bodymind offers generative corporalities that can support social change. Disability justice observes that “rights-based strategies often address the symptoms of inequity but not the root. The root of disability oppression is ableism and we must work to understand it, combat it, and create alternative practices rooted in justice.”²⁵ Disability rights are often most accessible to more privileged disabled people. Founders of the disability justice movement note that many categories of people are ignored in a rights-based framework, especially those who are marginalized in multiple ways and are not granted full recognition by the state, including immigrants, Indigenous peoples, those who are incarcerated, and those who are queer and trans, among many others.

From this position, disability becomes not just another identify-based framework, but one that connects to other movements for justice. The principles of disability justice are not

²⁴ David T. Mitchell and Sharon L. Snyder, *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment* (Ann Arbor: University of Michigan, 2015), 2.

²⁵ Sins Invalid, *Skin, Tooth and Bone*, 15.

only useful in working among people with disabilities but offer powerful advice for all ability levels in working towards transformative change. Multiply marginalized disabled people claim: “Our communities are often treated as disposable, especially within the current economic, political and environmental landscapes. There is no way to stop a single gear in motion — we must dismantle this machine.”²⁶ The critical disability studies method of tracing ableism shows the devaluing of entire populations rampant in today’s political landscape. Ableism compounds the racism and xenophobia against migrants. Ableism feeds white supremacy and white nationalism. Ableism feeds the stigmatization of queerness as disease. Disabled migrants, people of color, and queer people are all more likely to have their existence invalidated. As I have argued in this thesis, ableism also supports the positioning of Appalachia as a region in need of development or remediation. Those involved in disability justice are keenly aware of interlocking systems of oppressions, including those which have marginalized Appalachia as a region that is itself disabled.

Claiming disability matters. It matters to disabled people, who find value and meaning in connecting to others who experience ableism. But claiming disability should also matter to all of us, inside and outside of the academy, especially as we envision what the future for Appalachia might hold. As I have argued, Appalachia has faced a long history of disability stigma and othering, but there has also been organizing around shared experiences of disability and exclusion. Disability concerns resonate across many different movements for justice, and address concerns including labor, the environment, gender/sexuality, and caregiving. As more people experience disability-related issues, precarity, and loss,

²⁶ Ibid, 20.

especially given Appalachia's increased vulnerability to COVID-19,²⁷ finding organizing strategies that combat ableism and build these into our society, will become an even more important tool in the future.²⁸ Claiming disability helps us recognize disabled knowledges and world-building, which will prove especially valuable in times of extreme change that highlights our shared vulnerability. Moving away from a single-issue disability rights approach foregrounds the connections between disability and other struggles for justice and highlights the role that disability expertise can play in organizing for collective liberation.

²⁷ Matt Krupnick, "Appalachian Coal Communities Brace For Coronavirus: It's Going 'To Wipe Us Out,'" *Huffington Post*, April 4, 2020, https://www.huffpost.com/entry/coronavirus-coal-miners-black-lung_n_5e862723c5b6a949183323d7.

²⁸ For concrete examples of this, see "Access Statements," in *Skin, Tooth, and Bone*, 28-46.

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Vita

Rebecca Eli Long was raised in Norlina, North Carolina. They were homeschooled and graduated from high school in May 2013. They also completed a technical certificate in web design at Vance-Granville Community College in May 2013. The following August, Mx. Long enrolled in Appalachian State University, where they double majored in Anthropology and Art. Mx. Long completed the B.A. degree in December 2016 and graduated with both university and departmental honors.

In August 2018, Mx. Long returned to Appalachian State University for graduate study. They completed the M.A. degree in Appalachian Studies and a graduate certificate in Aging, Health, and Society in May 2020. During the course of the graduate program, Mx. Long held graduate assistantships in Appalachian Studies and Gender, Women's, and Sexuality Studies. They also were a Graduate Student Government Association Senator, President of the Autistic Students and Allies of the High Country, and informally organized disability justice groups on campus.

Mx. Long will continue their graduate education at Purdue University in August 2020. They have received a Purdue Doctoral Fellowship and will complete a dual-title Ph.D. in Anthropology and Gerontology.