

Radical Health



Radical Health

UNWELLNESS, CARE, AND LATINX EXPRESSIVE CULTURE

Julie Avril Minich



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For Ignacio & Simón, with love to Dominic



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BOOK COVER DESCRIPTION: The image on the cover is a charcoal drawing by Jaime Cortez entitled *Matriot* (2012). The drawing is a black-and-white ambiguous image in which a dark silhouette forms a black shape with gray blood cells floating within it. This dark shape suggests the face in profile of a human skeleton, while the image formed by the white negative space appears as a standing feminine figure holding the hand of a child. The book title and name of the author are written in red over this negative white space. The book title–*Radical Health*–appears just beneath and to the right of the feminine figure, with a larger font than the rest of the text. The subtitle–*Unwellness, Care, and Latinx Expressive Culture*–is written into the body of the feminine figure. The author's name–Julie Avril Minich–appears at the bottom left, just beneath the body of a child.



Introduction

Radical Health/Radical Unwellness

On September 9, 2009, President Barack Obama addressed a joint session of Congress to introduce what would become his signature legislative achievement: the Patient Protection and Affordable Care Act (ACA). Knowing that he faced stiff opposition, Obama was careful to preempt his critics, declaring: "There are also those who claim that our reform effort will insure illegal immigrants. This, too, is false. The reforms—the reforms I'm proposing would not apply to those who are here illegally" (White House 2009). Representative Joe Wilson (R-SC), a critic of Obama's proposal, could not contain himself. "You lie!" he shouted in an extraordinary breach of congressional etiquette that drew national attention. Wilson was censured by the House of Representatives and forced to apologize (Hooper 2009), and his outburst has been remembered as both an effort to sow disinformation and an expression of white resentment toward the first Black president of the United States. However, these characterizations—accurate as they are—miss another important truth: Wilson and Obama agreed on the exclusion of undocumented immigrants from a national health care plan (and coincided in their use of the pejorative descriptor illegal). Both Obama's



speech and Wilson's response thus demonstrate how anxieties about race and citizenship saturate national conversations about health care.

Five years after the ACA's passage, the arrest of Blanca Borrego demonstrates the cost of Obama's acquiescence to anti-immigrant sentiment. On September 3, 2015, Borrego went to an appointment at the new office of her longtime gynecologist and presented proof of insurance through her spouse's employer. Asked for identification, Borrego (who was undocumented) offered a fake driver's license. She was then taken to an exam room where she was arrested by a sheriff's deputy who escorted her out of the facility (Schiller 2015). The fact that a health care worker felt compelled to call law enforcement on a woman seeking medical treatment using private insurance reveals the stakes of debates over who should—and should not—access care.

Borrego's entire family felt the impact of her arrest: her spouse quit his job in fear of deportation, while her teenage son (who had a work permit through the Deferred Action for Childhood Arrivals, or DACA, program) became the family's sole wage earner. Likewise, measures to terrorize undocumented immigrants reverberate throughout Latinx communities. In part this is because many Latinx people, like Borrego, belong to mixed-status families, but it is also (and more importantly) because the figure of the undocumented immigrant is a crucial rhetorical device in the racialization of Latinx people. Historians have demonstrated that immigration restrictions and border enforcement are not simply the result of racist biases but are mutually constituted with them (Hernandez 2010; Lew-Williams 2018; Martinez 2018; Molina 2014; Ngai 2004). ¹ To understand the racialization of Latinx communities as intertwined with anti-immigrant sentiment, then, is not to conflate the categories of "Latinx" and "immigrant"—or even to suggest that all Latinx people identify with or as immigrants—but rather to note the critical function of anti-immigrant discourse in the social construction of Latinidad more broadly.

Yet even as Borrego's family and community felt the effects of her arrest, they also mobilized in response. As her son supported the family on a waiter's pay, Borrego's daughter took to the media in protest: "My mom is a good person. . . . She doesn't deserve what's going on" (Garcia-Ditta 2015). Like Borrego's daughter, Latinx cultural workers—writers, filmmakers, musicians, performers, visual artists—create narratives that counter the messages of a xenophobic and white supremacist national culture. This book focuses on one subset of this cultural production: art (especially literature) addressing the relationship between Latinx communities and the health

care system, advancing an ethic of radical health that embraces racialized, disabled, and otherwise devalued bodyminds.²

Why Health?

Radical Health: Unwellness, Care, and Latinx Expressive Culture argues that Latinx expressive culture can offer a powerful intervention in contemporary US health politics. First, it elaborates how certain Latinx artists expose ideologies of health as an engine of racism, following geographer Ruth Wilson Gilmore's famous definition of racism as "the state-sanctioned or extralegal production and exploitation of group-differentiated vulnerability to premature death" (2007, 28). In particular, I trace how these cultural workers critique notions of health as the result of personal behavior that render Latinx communities radically unwell by eliding structural determinants of health. Second, and more importantly, I explore the politics of radical health emerging from cultural artifacts that present health not as individual duty but as communal responsibility. This latter thread of my argument, which constitutes the bulk of my analysis, examines texts by Latinx artists who seek to elucidate the collective and societal aspects of wellbeing, presenting health as a political concern rather than a purely individual, medical one. Here I claim a role for artistic work and cultural studies scholarship in the effort to combat both health stigma and racial health disparities.

I use the word *radical* throughout this study to emphasize that my focus is not on reforming health care but rather on fundamentally reimagining what health means and how health resources are distributed. I use the word health to signal my commitment to the field of disability studies as well as to clarify my position within it. Disability studies, as Jina B. Kim has observed, partially owes its urgency to the fact that, in the contemporary United States, "disability, debility, and illness have emerged as primary arenas for racialized punishment" (2020, 266). At the same time, a tendency among scholars in the field to reject (rather than critically engage with) discourses of health, cure, and medicalization can leave it poorly equipped to address this concern.³ In fact, Black feminists Moya Bailey and Izetta Autumn Mobley highlight the long-standing critique by disability scholars of medical models of disability as one of the field's major barriers to advancing racial justice: "While certainly the medical model is a problematic trope, it may signal differently to communities that have tried for many decades to receive the most elementary care only to be refused. As uncomfortable as it may make

those of us engaged in the Disability Studies field, some communities are actually yearning for not only care but treatment and cure" (2019, 28). In titling this book *Radical Health*, I posit that a reassessment of health can contribute to what Kim (2017, 2021) calls a crip-of-color critique and what Sami Schalk and Kim (2020) call a feminist-of-color disability studies, terms that signal the need for scholarship that is both anti-ableist and anti-racist.

Crip-of-color critique is not merely a subset of disability studies that combines perspectives from ethnic studies with the insights of disability theory; it is a substantially new body of knowledge that reexamines what disability is, what disability studies does, and who disability theory is for. In other words, rather than merely diversifying the field or unsettling its long-acknowledged whiteness, crip-of-color critique remakes disability studies. The intellectual precursors to crip-of-color critique emerge not solely from disability studies but also from critical race studies, and most importantly from Black studies. For instance, the term crip-of-color critique is not simply a clever restatement of Roderick A. Ferguson's now-famous phrase queer-of-color critique, but rather an extension of Ferguson's effort to debunk "the idea that race, class, gender, and sexuality are discrete formations, apparently insulated from one another" (2004, 4), and to identify processes of racialization within cultural formations that present themselves as unrelated to race. Schalk and Kim insist that critical race theories must "inform work in disability studies as a whole even when people of color are absent as sites of analysis" (2020, 33). Similarly, Sony Coráñez Bolton (2023) has made the provocative move of claiming that the focus on colonized embodiment within Filipinx studies constitutes it as a mode of crip theorizing. Although the term crip-of-color critique is relatively new in the disability studies lexicon, the insistence that a focus on race and racialization fundamentally changes the field is not. In a foundational special issue of MELUS on race and disability, Jennifer C. James and Cynthia Wu urge disability scholars to consider "how disability has always been racialized, gendered, and classed and how racial, gender, and class difference have been conceived of as 'disability'" (2006, 8). At the same time, and more pointedly, Chris Bell suggests that a disability studies intent on equating "visibility with inclusivity" (2006, 279)—that is, citing examples of disabled activists and scholars of color without committing to the intersectional analysis they demand—might more accurately be named white disability studies.

While disability studies scholars often locate the origins of the field in disability rights activism, scholars who align their work with crip-of-color

critique often look as well to activist work in which disability does not always present as the primary concern. In describing the activism that informs her theory of Black disability politics, for instance, Schalk notes that "the articulation and enactment of Black disability politics do not necessarily center traditional disability rights language and approaches, such as disability pride or civil rights inclusion, instead prioritizing an understanding of disability within the context of white supremacy" (2022, 5). Rather than disability rights, crip-of-color critique often emphasizes disability justice. As Mia Mingus (2011) defines it, disability justice means "moving away from an equality-based model of sameness and 'we are just like you' to a model of disability that embraces difference, confronts privilege and challenges what is considered 'normal' on every front." For Patty Berne (2015), a "Disability Justice framework understands that all bodies are . . . caught in these bindings of ability, race, gender, sexuality, class, nation state and imperialism, and that we cannot separate them." The activism that forms the theoretical base of crip-of-color critique, then, centers not just disability but multiple and mutually reinforcing systems of oppression; the embrace of interdependence over independence; and the desire for revolution over reform.

A survey of twentieth-century Latinx history demonstrates how ideologies of health and ability have shaped the social and political construction of Latinx identities and the racialization of Latinx people. For instance, 1904's Gonzales v. Williams, the US Supreme Court case that established Puerto Ricans as "noncitizen nationals" and set the legal precedent for the secondclass citizenship that Puerto Ricans still experience, was set in motion when immigration inspectors at Ellis Island noticed the visible pregnancy of Isabel González, deemed her "likely to become a public charge," and placed her in detention (Erman 2019). Latinx history offers a record of how disability and health affect the US immigration system as well as how that system affects the bodies of migrants: Alexandra Minna Stern (1999), Natalia Molina (2006), and John McKiernan-González (2012) detail how Latinx migrants have been treated as vectors of disease, while Mary E. Mendoza (2017) and Seth Holmes (2013) demonstrate the debilitating living and working conditions that Latinx agricultural workers experience. Eugenic ideologies of health, meanwhile, subject Latinx people regardless of citizenship status to coercive sterilizations and reproductive abuse, as Laura Briggs (2003), Elena R. Gutiérrez (2008), and Natalie Lira (2021) show.

Responding to these histories, Latinx struggles for racial justice have often been organized around concerns of health and wellbeing. The activism

of César Chávez for the health and wellbeing of agricultural workers is memorialized in a national monument, a major motion picture, and the street names of several major US cities, but the health advocacy of the New York Young Lords, which organized hospital takeovers, offered testing for tuberculosis and lead exposure, and staged a Garbage Offensive to protest discriminatory city sanitation services, also merits close attention (Fernández 2020; Morales 2016; Wanzer-Serrano 2015). Schalk and Kim argue that such activist work should not be seen merely as an underrepresented object of analysis in disability studies but should be treated as an unacknowledged contribution to disability theory because it produces new knowledge about the intersection of race, gender, and ability.⁴

This study begins with texts published in the mid-1990s and extends to the contemporary period. In the United States, this period saw expanded opportunities for people with disabilities to participate in public life, a significant retraction of the social safety net, and vociferous debates over immigration policy—all of which come to bear on current public discourse related to the US health care system. The writers and artists whose work I examine reflect these social conditions in their work through their inclusive representations of diverse bodyminds, their concern for how ideologies of individual self-reliance prevent vulnerable people from accessing care and support, and their direct engagement with the consequences of border enforcement. The texts I analyze in this book thus capture and respond to these national conversations, offering not policy analysis but aesthetic renderings of the relationship between personal wellbeing and social climate. In particular, three laws from the 1980s and 1990s shape the political environment from which these texts emerge: the 1986 Immigration Reform and Control Act (IRCA), which formalized the status of approximately three million undocumented residents of the United States and created new immigration control infrastructure; the 1990 Americans with Disabilities Act (ADA), which prohibited disability discrimination and guaranteed employment and educational opportunities for people with disabilities; and the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA), which (as President Bill Clinton proudly proclaimed) "ended welfare as we knew it." None of the texts I examine in this book directly mentions these laws by name, but they all respond to (and in some instances capitulate to) a social climate marked by scrutiny and resentment directed toward people who access increasingly scarce public resources and by the sense that people's wellbeing is a matter of personal (rather than public or collective) responsibility.

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The first two laws, signed by Republican presidents, seem to enact policies to the left of the current political center in the United States; the latter, signed by a Democrat, constitutes the kind of decimation of safety nets typically attributed to politicians on the right. (Together, these laws demonstrate how far to the right both US political parties have moved in the past half-century.) The IRCA, for instance, has been retrospectively characterized as an "amnesty program" but also spurred anti-immigrant backlash (Abrajano and Hajnal 2015). Meanwhile, the ADA secured the right to work for disabled people but not the right *not* to work; as Sunny Taylor (2004) reminds us, it reinforced the idea that people with disabilities should seek employment rather than relying on public benefits.⁵ Finally, PRWORA both institutionalized the notion of "personal responsibility" that has figured so prominently in debates over the ACA and exacerbated the need for health care reform by severely limiting Medicaid eligibility.⁶ Public debates about these laws echo in those surrounding the ACA, which in addition to presenting the undocumented as unworthy of health care also reinforce the idea that people forced to rely on the state for life-sustaining resources are irresponsible and undeserving. For instance, during a 2017 push to repeal the ACA, Representative Jason Chaffetz (R-UT) suggested that the reason many people could not afford health care was their smartphone purchases: "Americans have choices," he told CNN. "And they've got to make a choice. And so, maybe rather than getting that new iPhone that they just love and they want to go spend hundreds of dollars on that, maybe they should invest it in their own health care."7

I rehearse this history because, as I finish writing this book in the immediate aftermath of Donald Trump's White House occupancy and the ongoing devastation of the COVID-19 pandemic, it feels urgent to remember that this moment, while dire, is not exceptional. I began this book in 2014, the year most provisions of the ACA came into effect. At that time, I held an unequivocally critical stance toward the law: I considered its exclusion of undocumented immigrants both morally reprehensible and bad public health practice, and I opposed as well its promotion of an individualist approach to health.⁸ By the time I finished my first draft of this manuscript, things had changed dramatically. It was 2020, more than three years into Trump's time in the White House; the future of the ACA was (and is) uncertain; increasingly draconian policies were being enacted against immigrants; and debates about public health measures to curb the spread of COVID-19 were fiercely underway. Indeed, in the context of the COVID-19 pandemic, the idea of health as an individual responsibility has turned deadly, with a

prominent and vocal minority of the US population loudly and violently asserting its right to refuse public health precautions and endanger the lives of others. This book, then, which began as a polemic against the ACA, became an effort to expose and dismantle the racial animus that undergirds national conversations about public health and to illuminate how Latinx cultural workers have reimagined health and wellbeing.

Radical Health thus treats the work of contemporary Latinx cultural workers as a source of theoretical insight about disability, health, and wellbeing. It tells the stories not of the twentieth-century social actors, like Isabel González or the Young Lords, who contested racializing discourses of health and racial health disparities, but of contemporary Latinx cultural workers who have demanded access to health resources even as they have also sought to redefine health itself. My use of the phrase radical health captures how these cultural workers advance a critique of health (as a punitive ideology used to devalue and disparage people whose bodily practices do not conform to social norms) even as they seek to claim it.

Health as Racializing Ideology

To illuminate how the texts I study reimagine health, I first address the ideological function of health as an instrument of racialization. The aforementioned debates about the passage and implementation of the ACA are a useful starting point both because of the ACA's exclusion of undocumented immigrants and because of what these debates reveal about who is understood to deserve health and who is not. I am not, of course, the first to criticize the ACA, a law that historian Colin Gordon (2018) calls a "spectacularly imperfect solution to our healthcare crisis." There are many good critiques of the ACA; mine focuses on the law's designation of particular people as ineligible. The narrative that some people simply had to be excluded for the ACA to pass reifies the idea that the health of the nation depends on withholding health from certain populations. ¹⁰ Of course, this idea is patently false. Health is not a finite resource that grows scarcer as it is made more widely available. If the COVID-19 crisis has taught us anything, it is that the *more* people within a community have access to health resources—including not just doctors and medicines but also paid sick leave, safe childcare, food security, and safe housing—the healthier everyone in that community can be. In an earlier assessment of the repeated failures to create a national health care plan in the twentieth-century United States,

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Gordon (2003) faults not the overreach of activists who attempted to cover too many people (as common explanations have it) but reformers' willingness to compromise and leave people out. By accepting certain exclusions as necessary, advocates of "universal" health care affirmed "distinctions between deserving and undeserving citizens" (9), undermining not only their cause but public health itself. By declaring from the outset that undocumented people would be ineligible for benefits, advocates of the ACA effectively opened the door to further discussion of whether certain categories of people deserve health care at all—a conversation that has left the law itself precarious.

The flaws of a health care system that denies care to entire populations came dramatically to light in 2020 with the spread of COVID-19, even as the pandemic also laid bare the impulse to blame under-resourced populations for their poor health outcomes. In the United States, for instance, death rates in Black and Latinx communities have been blamed on comorbidities resulting from "unhealthy" lifestyles (like fatness and diabetes), rather than on unequal health care access, on the overrepresentation of Black and Latinx people among the essential workers most exposed to the coronavirus that causes COVID-19, or on patterns of residential discrimination that concentrate Black and Latinx people into high-density dwellings where social distancing is difficult. Meanwhile, once a COVID-19 vaccine became available, the (initially) lower vaccination rates in Black and Latinx communities were immediately attributed to vaccine hesitancy rather than to lack of access. When vaccines in the United States were in short supply, debates raged about whether certain categories of people (including fat people, smokers, and undocumented immigrants) should receive them, suggesting a widespread belief that certain people deserved to die of a preventable illness. Once the vaccines became widely available, vaccine mandates were framed as an imposition on healthy people, whose personal freedom to refuse vaccination was valorized above the lives of the vulnerable people that universal vaccination would protect. The toll of the COVID-19 pandemic—and the ways in which racialized death was normalized and rationalized—reinforces a pointed critique of the US health care system by the disability scholar Nirmala Erevelles: "Why do some bodies matter more than others?" (2011, 6).

The idea that personal behaviors or beliefs are the primary cause of health disparities is linked to what the sociologist Robert Crawford calls *healthism*: "the ideology of individual responsibility for health" (1980, 367).¹¹ To be perceived as deserving health in a society that embraces healthism, one must care for one's body according to very precise social norms: avoiding tobacco

and other controlled substances, eating a diet deemed nutritious, wearing sunscreen, refusing to engage in risky sex practices, and exercising often. Meanwhile, those seen as undeserving often experience bodily conditions, erroneously believed to result solely from irresponsible personal choices, that have a disproportionately adverse effect in communities of color and among people of lower socioeconomic status: fatness, asthma, diabetes, sexually transmitted infections, addiction, high-risk or stigmatized pregnancies, mental illness, and some cancers and neurological differences.¹² Healthism pervades the political rhetoric of liberals and conservatives alike; it surfaces in Republican efforts to dismantle the ACA as well as in local ordinances (many sponsored by Democrats) banning the construction of new fast-food restaurants or dollar stores, out of the belief that such establishments promote "bad" food choices among the poor (Capelouto 2019; Chandler 2015; Ward 2013). It is not, I believe, coincidental that Obama, the president who finally did expand health care access, was tall, normatively attractive, and personally invested in performing health (he took pains to conceal his cigarette addiction and highlight his time on the basketball court when he moved into the White House)—nor do I think it coincidental that the signature charitable cause of his spouse, Michelle Obama, was an effort called Let's Move! focused on individual health behaviors like exercise and the consumption of fresh, unprocessed foods.¹³

The notion that people are personally responsible for their own health also aligns with an idea long critiqued by disability scholars: what Robert McRuer (2006) calls compulsory able-bodiedness. McRuer defines compulsory able-bodiedness as the commonsense agreement that "able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for" (9). Compulsory able-bodiedness is often understood to describe the demand that people perform to their maximum ability at all times (taking the stairs instead of the elevator, even if it means exhaustion later; refusing necessary accommodations at work or at school to avoid the appearance of "preferential treatment," etc.) and the emphasis of charities promoting the "search for a cure" rather than improvements to the quality of life for people with disabilities. But compulsory able-bodiedness is also at work in the mandate to protect one's health at all times and at all costs. Under a system of compulsory able-bodiedness, behaviors that might foster a sense of wellbeing but are not considered "healthy" (like eating a piece of cake, smoking a joint, or having anonymous sex) are subject to shaming and punishment. Those unable or unwilling to consistently perform

normative health behaviors are seen not merely as responsible for their own ill health but as a burden on society, a drain on valuable resources, unworthy of care or protection, and ultimately disposable.

Radical Health interrogates how healthism and compulsory ablebodiedness justify the health disparities that affect Latinx communities. While the case of Blanca Borrego, criminalized for seeking medical care, represents the overt denial of care to Latinx people, healthism and compulsory able-bodiedness are more insidious: they present health concerns affecting Latinx communities, from HIV/AIDS to diabetes, as the result of pathologized personal behaviors or cultural attributes rather than structural inequities. There are echoes here of what the historian Alan M. Kraut calls "medicalized nativism" (1994, 3). Medicalized nativism, as Priscilla Wald observes, "involves more than superimposing a disease threat on an unfortunate group" (2008, 8); it also links disease to "dangerous practices and behaviors that allegedly mark intrinsic cultural difference" and that express "the destructive transformative power of the group" (8). Radical Health begins at the intersection of medicalized nativism with neoliberal notions of individual responsibility, where the "dangerous practices and behaviors" attributed to Latinx people are used to explain the health concerns affecting their communities and where racialized health disparities become an argument against (rather than for) universal health care.

Dominant ideas about health are not merely the result of racial bias; they can foment white supremacy. Sociologist Eduardo Bonilla-Silva identifies "the curious enigma of 'racism without racists'" (2014, 4), a phenomenon in which purportedly race-neutral policies and ideologies produce racially unequal outcomes.14 Health, I argue, is one apparently race-neutral ideology that perpetuates racial inequality. When poor health is understood as the result of bad personal choices and not the systemic denial of access to health-sustaining resources, then entire communities are blamed for their illnesses, impairments, and deaths. Furthermore, when health is construed as the result of good personal choices (motivation, restraint, discipline), those experiencing illness are constructed as indolent, gluttonous, and negligent—adjectives with a long history in racializing discourse. In this way, health can function as both an outcome and a source of racial injustice. Therefore, while the phenomenon of "racism without racists" described by Bonilla-Silva operates across numerous sites, health is a particularly important one—and one that I believe has been underexamined as a key theme in Latinx aesthetic representations.

Radical Health

Against the racializing ideologies of health just described, this book examines the work of Latinx artists advancing a politics of radical health. I define radical health as a vision of health that simultaneously emphasizes its structural dimensions and refuses to treat it as a measure of human worth. Here I offer two distinct—even at times incongruous—lines of analysis. First, I address how Latinx expressive culture makes visible the context in which people make health decisions. In response to healthism, compulsory ablebodiedness, and the neoliberal policies they promote, the texts examined in the following chapters reveal factors beyond individual control—access to nutritious food, medical care and information, clean air and water, and cultural representations portraying one's life as valuable and worth living that affect physical and mental wellbeing. Second, I emphasize how the texts I study present the value of Latinx lives independently of health status. These texts depict people who are HIV-positive, fat, diabetic, and otherwise labeled as unhealthy in ways that reject the stigma of unhealth. Latina fat activist Virgie Tovar (2015) exemplifies this latter strategy: "There are . . . those whose politics align largely with my own who are committed to pleading a case that my body is a failure that is 'not my fault' . . . But I'm not interested in exonerating myself. And perhaps more importantly, there is nothing that needs exonerating." From this angle, one might note that this book could just as easily be titled Radical Unwellness (which was, in fact, one of my early working titles), since some of the texts I examine offer such sharp critiques of the conflation of a person's social value with their health status that they can be read as an embrace of unhealth. Ultimately, however, I chose to put the word *health* in my title not to reaffirm its value but to signal my commitment to interrogating it.

At first glance, the fact that so many of the artists I study simultaneously critique the structural factors that lead to racial health disparities *and* celebrate the bodies shaped by these disparities might seem contradictory or even incoherent (and, as my discussion of individual texts will show, contradictions and incoherencies do arise). These contradictions, however, illuminate a larger theoretical conundrum. As crip theorist Alison Kafer asks: "How can we attend to 'serious health problems' while also deconstructing the stigma attached to those problems or even historicizing the very construction of such conditions as problems?" (2013, 159). Kafer's question is motivated by an effort to find coalition between disability and environmental justice activists, but given the systemic denial of health

care to poor people of color, it has much wider implications. Answering Kafer's question requires nuancing disability rights discourses that celebrate nonnormative bodies without critiquing the social conditions that produce them. Jasbir K. Puar, for instance, notes the limitations of disability scholarship and activism that is singularly focused on reclamation: "In a context whereby four-fifths of the world's people with disabilities are located in what was once hailed as the 'global south,' liberal interventions are invariably infused with certitude that disability should be reclaimed as a valuable difference—the difference of the Other—through rights, visibility, and empowerment discourses—rather than addressing how much debilitation is caused by global injustice and the war machines of colonialism, occupation, and U.S. imperialism" (2017, xvii). Erevelles pointedly asks: "How is disability celebrated if its very existence is inextricably linked to the violence of social/economic conditions of capitalism?" (2011, 17). And while the tension between disability pride and the effort to address health injustice may lack a definitive resolution, I believe it is urgent to work from that tension in a political moment when communities of color and the poor are uniquely vulnerable to disease and impairment even as such communities are collectively blamed and stigmatized for their ill health. This book therefore centers the work of artists who embrace debilitated bodies while critiquing systems of debilitation.

Although my methods are primarily those of the literary critic, I have found that attending to the vision of radical health offered by the texts discussed in this study requires citing scholars from outside literary studies as much as scholars from within it. Like literary critics Paula M. L. Moya and John Alba Cutler, I understand literary scholarship as fundamentally and necessarily in conversation with the work of other disciplines, particularly the social sciences, and I understand art of all kinds as an endeavor that is both aesthetic and ideological. In different contexts, Moya and Cutler have both demonstrated how the methods of literary criticism—including close reading, formal analysis, and theoretical engagement—serve as an intervention into pressing social concerns. Moya asserts that literary criticism has a necessarily sociopolitical dimension, as a "close reading of a work of literature can . . . serve as an excavation of, and a meditation on, the pervasive sociocultural ideas—such as race, ethnicity, gender, and sexuality—of the social worlds . . . within which both authors and readers live" (2016, 8-9). Cutler, meanwhile, argues that the work of social scientists is often more literary than acknowledged; within it, our social world "is never simply observed—it is produced and reproduced" (2015, 8).

In addition to drawing from literary studies, critical ethnic studies, and crip-of-color critique, I take inspiration from the rejection of respectability politics that characterizes queer-of-color critique. Respectability politics, as Juana María Rodríguez notes, allege "that in order to enter the fold of collectivity, be it familial or revolutionary, we must first be liberated of our sexual deviance and our politically incorrect desires" (2014, 11). Like Rodríguez, I am interested in bodyminds that "exceed the norms of proper corporeal containment" (2014, 2), but where Rodríguez focuses on the eruption of bodily excess in sexual practice, Radical Health examines it in medical scenarios, where the "politically incorrect desires" precluding entrance into the collectivity might include simple carbohydrates or sex without condoms (however vanilla that sex might otherwise be). As Lisa Marie Cacho observes: "Ascribing readily recognizable social value always requires the devaluation of an/other, and that other is almost always poor, racialized, criminalized, segregated, legally vulnerable, and unprotected" (2012, 17). To Cacho's list of devalued others I add the radically unwell: the diseased, the disabled, the unhealthy, and the debilitated.

One salient example of how the effort to claim the value of some can devalue others is visible in some public health scholarship emphasizing the Latinx Health Paradox. Also known as the Hispanic Health Paradox and the Healthy Latino Paradox, this concept describes a phenomenon observed by public health researchers that Latinx immigrant populations tend to have better health outcomes than their socioeconomic status would predict. As originally theorized by the sociologist Rubén G. Rumbaut, the Latinx Health Paradox seems at first glance to challenge the "ethnocentric assumptions" (1997, 490) that position immigrants from Latin America as a burden on the US health care system. Yet there are reasons to be cautious about characterizing Latinx communities as "a super-healthy population with differing health promotion and services needs" (Vega and Amaro 1994, 40). Medical anthropologist Seth Holmes (2013) notes the vast intra-ethnic diversity within the category "Latinx" and observes specifically that migrant and seasonal agricultural workers—a category in which immigrants from Mexico and Central America are overrepresented—experience much poorer health status than nearly all other workers. And, most relevant to my argument, many researchers have noted that the Latinx Health Paradox relies on essentializing notions of culture and ignores structural factors that influence health (Castañeda et al. 2015; Viruell-Fuentes, Miranda, and Abdulrahim 2012). Scholars who invoke the Latinx Health Paradox tend to speculate about behaviors linked to cultural belief systems that offer health

benefits, but, as Edna A. Viruell-Fuentes argues, this approach "runs the risk of lending support to victim-blaming explanations for health outcomes" since the "idea of culture as a 'source of dysfunction' can easily flow from this line of thinking" (2007, 1525). The problems of leaning too heavily on discourses like the Latinx Health Paradox are also made visible in scholar-ship from adjacent fields, particularly Asian American studies scholarship examining the role of health in constructing a "model minority" identity (Lee 2021; Shah 2001).

Just as the focus on health distinguishes *Radical Health* from disability scholarship that takes a purely critical stance toward healing and cure, so too does my emphasis on crip-of-color critique differentiate this study from literary criticism rooted in a medical humanities approach known as narrative medicine. Developed by the physician-scholar Rita Charon, narrative medicine refers to "medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by stories of illness" (2006, 3). While I share Charon's interest in the subjective experience of health and unwellness, and applaud her efforts to integrate narrative theory into medical education, I believe that cultural texts have more to offer than the fostering of individualized compassion, empathy, and care; in addition, they offer a means of imagining our social world otherwise and a proposal for structural change. ¹⁵

The texts examined in this book engage with health on both individual and structural levels, making visible the larger context in which people make health decisions but also revealing people's individual (sometimes imperfect, always complicated) navigation of structural constraints. While the task of the social scientist is to note and describe this navigation, the task of the artist is to show us what it looks and feels like in practice, undertaken by people with messy desires, limitations, and flaws. Because the sustained analysis of cultural artifacts requires a simultaneous examination of both individual behaviors and larger systems, cultural criticism is an important resource for understanding health disparities. This is especially true because the individual threads of an argument in cultural studies scholarship don't always align perfectly: different artists approach social concerns differently, and even a singular artwork may be characterized by internal incongruities whose convolutions mirror those of the thorny social issues it navigates. Thus, having elaborated my argument, I now turn to a work of art that illuminates the tensions within it: the performance manifesto Your Healing *Is Killing Me* by Chicana playwright and performance artist Virginia Grise.

PAUSE: Virginia Grise, Your Healing Is Killing Me

Your Healing Is Killing Me (YHIKM) follows the journey of an artist with severe eczema to find relief from her symptoms. As a chronic condition of unknown cause, linked to genetics but triggered by environmental factors and stress, eczema prompts the speaker to meditate on both the injustices of a capitalist health care system and the intergenerational PTSD (caused by migration, war, and sexual violence) that affects her family. The text, in other words, substantiates a lament from disability justice activist Leah Lakshmi Piepzna-Samarasinha: "Everyone I know longs for healing. It's just hard to get. The good kind of healing: healing that is affordable, has childcare and no stairs, doesn't misgender us or disrespect our disabilities or sex work, believes us when we're hurt and listens when we say what we need, understands that we are the first and last authorities on our own bodies and minds" (2018, 97–98). YHIKM layers the speaker's current life as a working artist with memories of childhood trauma and experiences with healers from curanderas to acupuncturists to dermatologists, showing that finding the "good kind of healing" requires her to address not just one physical ailment but longer histories: neoliberal economic policies that curtail possibilities of social mobility, making survival as a working artist tenuous; the Vietnam War and its effect on her father's mental health; her mother's and sisters' migrations between Mexico and the United States; and her childhood experiences with sexual violence. The speaker tries numerous treatments, some of which help temporarily and many of which create new problems (like the steroid cream that induces dependency, rapid weight loss, and mood swings).

In addition to moving between personal and structural registers, *YHIKM* also engages the complexity of what Eunjung Kim (2017) calls "curative violence." The text contains a staunch critique of capitalist influences in the health care system, detailing the barriers to treatment faced by a working artist with no health insurance, but its emphasis on finding a cure for the speaker's eczema also places it in tension with what activist Eli Clare calls the "anti-cure politics" (2017, 60) of the mainstream disability movement. Another potential concern for some might be the treatment that the speaker ultimately finds for her eczema—bone soup, cooked weekly by her lover: "Bone soup builds immunity, helps with inflammation and digestion. Some say it even fights cancer. After all those visits to the nice lady doctor and the fancy dermatologist and the cynical acupuncturist, I found out that what I needed was right in my kitchen the whole time" (Grise 2017, 82). While the fact that the speaker finds a treatment option outside of a capitalist health

industry drives home the critique of profit-driven health care, the experience of receiving invasive and patronizing health recommendations (often in the form of "holistic" medicines or dietary changes) from well-meaning strangers is a common and frustrating experience for many people with disabilities and chronic illnesses. In other words, despite its benefits to the speaker of this particular text, bone soup may be as ineffective and harmful for some chronically ill people as for-profit medicine.

Yet as the speaker of YHIKM delves into the possible causes of and treatments for her eczema, she ultimately arrives at an exhaustive list of things that are killing her (that is, not only worsening her eczema but shortening her life), a list that covers medicine, the health care system, food production and distribution systems, economic inequality, white supremacy, the lack of a viable political left in the United States, gender roles, and more. While the desire for relief that permeates YHIKM and the cure that results might sit uneasily with some disability scholars and activists, Grise's delicate negotiation of the need to balance critique of the health care system with investment in healing places her work firmly in conversation with scholars and activists like Eli Clare and Eunjung Kim, who seek to complicate how disability communities engage with cure.

It is important, then, to note that although the *plot* of *YHIKM* ends with a cure, the *text* does not. Here I refer back to my earlier point that while the plot of *YHIKM* follows the speaker's journey to find relief for eczema symptoms, the monologues that make up the manifesto tell a comprehensive story of the speaker's experiences with trauma, illness, and healing. After sharing her experience with relief from her symptoms via bone soup, the speaker offers a proclamation suggesting that even if *she* has found a solution that works for her, the structural problems that exacerbated her eczema remain intact:

Capitalism is toxic. No amount of body butter or eczema creams will act as a salve for its toxicity. As a system it cannot be fixed. The only way to defend ourselves against it is to destroy it. The only way to destroy it is to create something better. In the process, we must be willing to assess, to prepare, to study, to fight, but we must also be willing to listen to ourselves and each other, to change, to transform, to care for ourselves and each other. . . .

I am an artist. And as an artist, I believe that my greatest creative project is to imagine something, something better, where our dreams matter, where as a people we are free. (Grise 2017, 83)



This conclusion prompts spectators to understand health and wellbeing as concerns that demand political solutions even when individual symptoms are resolved. YHIKM further makes a claim for art as the medium through which people are able to imagine better ways of ensuring each other's wellbeing. While the writers and artists discussed throughout this book differ in their assessments of the health care system, the kinds of bodily conditions they address, and their strategies for combating the stigma of unwellness, their work is united by the effort to make an aesthetic, imaginative argument for a politics of radical health.

Latinx Expressive Culture (or "Latino Is Not a Politic")

My engagement with Grise in the previous section requires that I end this introduction with some final comments about why I have specifically located my exploration of radical health in a group of interpretive objects that I label as Latinx expressive culture—a category that, as much recent scholarship demonstrates, merits some pressure. In fact, in YHIKM, Grise's speaker pointedly rejects Latinx as a basis for collective action (and, implicitly, as a basis for collective aesthetics as well), asserting that "Pan-Latino(ism) is killing me, as Latino is not a politic nor an ideology and does nothing to prepare us to defend ourselves against what is actually killing us" (2017, 57). Indeed, although I argue that a conceptualization of radical health comes into focus from the collective analysis of a range of contemporary Latinx cultural artifacts, not only do I seek to avoid imposing ideological uniformity on the texts I examine, I want to be clear that I don't even love (or agree with) them all equally. As just one salient example of the dissonance that surfaces between the writers and artists I discuss, chapter 2 (on diabetic representation) juxtaposes a piece coauthored by Grise, a committed prison abolitionist, against an autobiography by Supreme Court Justice Sonia Sotomayor, who began her career as a prosecutor. Of course, Latinx studies as a field has always understood Latinidad as what the political theorist Cristina Beltrán calls "a site of permanent political contestation" (2010, 9) and not as a descriptive category; some of the interdiscipline's most important work involves interrogating its very constitution. For instance, literary critic Ralph E. Rodriguez has argued against deploying Latinx "as a taxonomical and aesthetic category" (2018, 3) in cultural criticism, noting that even if such labels are "operational in social and political arenas,

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that does not mean they have an aesthetic force" (12). Although mindful of these warnings, I have nonetheless used *Latinx* throughout this book because of the force that the term continues to hold in the field of public health. For me, using *Latinx* to denote a population often described in medical literature as "Hispanic" offers a way to bring into conversation cultural workers engaging with health care politics, as well as a means of negotiating between the function of the ethnic label to homogenize, categorize, and pathologize (on one hand) and the artistic and activist projects offering possibilities for redefinition, critique, coalition, and solidarity (on another).

The possibility of coalition and solidarity also means being accountable to the debts that Latinx studies owes to other ethnic studies fields. In this introduction, I have already noted the pivotal role of Black disability scholars in creating the theoretical infrastructure for the body of knowledge now described as crip-of-color critique. Like disability studies, Latinx studies owes a profound debt to Black studies, a debt to which Puerto Rican performance studies scholar Sandra Ruiz eloquently alludes when she reminds us "what Blackness unearths about life and death that other analytics might not ever understand about existence" (2019, 17). As I was researching the chapters that follow, the work of Black studies scholars on HIV/AIDS (Chris Bell), diabetes and metabolic disorders (Richard M. Mizelle Jr., Anthony Ryan Hatch), racialized gender violence (Beth E. Richie), and madness (La Marr Jurelle Bruce, Therí A. Pickens) has been essential for my thinking. In addition, scholars of Asian American studies (Nayan Shah, James Kyung-Jin Lee) have illuminated the discursive links among race, citizenship, migration, and ideologies of health. Ultimately, I find that health functions as what Molina (2014) calls a racial script—a racializing narrative that is enacted both in institutional settings and in mundane, everyday interactions; that draws its force from the way it connects to cultural representations and practices used to racialize different groups in different historical periods; and that is available for racialized groups to seize and repurpose (what Molina calls "counterscripting"). In other words, because health works as a racial script, racial health disparities experienced by Latinx people need not be exclusively identifiable as "Latinx concerns" nor be experienced in the same way by all Latinx people (or even racialize all Latinx people in the same way) for their racializing effect to matter.

The COVID-19 crisis in the United States helps to illustrate this point. When the novel coronavirus causing COVID-19 was first identified in the United States, it ushered in a wave of racist attacks on Asian and Asian

American communities that (as of this writing more than two years later) continue to escalate. This, in turn, fueled both a more generalized medical racism that prompted immigration restrictions and a broader anti-immigrant sentiment that also affected some (but not all) Latinx communities. By the late spring of 2020, the US-Mexico border was closed, and immigrants from Mexico and Central America were being specifically blamed for COVID-19 outbreaks in rural parts of the southern and midwestern United States. Health and Human Services Secretary Alex Azar attributed outbreaks in meatpacking facilities (Cancryn and Barrón-López 2020) to the "home and social" aspects of workers' lives (not their working conditions), while Florida Governor Ron DeSantis described outbreaks in his state as resulting from immigrant agricultural and construction workers "packed in there like sardines" (Reston 2020) on the buses transporting them to their jobs. Azar and DeSantis did not just devalue the lives of the workers responsible for feeding the rest of the country during a period of disruption in the national food supply but drew from and recirculated the racial script blaming the crisis on Asians and Asian Americans to stigmatize Central American and Mexican immigrant communities, thereby normalizing the disproportionate caseloads and death rates in Latinx communities overall. Like the incidents recounted at the beginning of this introduction—which addressed the convergence of debates over immigration and health care policy—these stories about how a public health crisis heightened and fueled the racialization of diverse Latinx communities across the United States illustrate the need for a specific analysis of how diverse Latinx artists have created counterscripts to disrupt the systemic devaluation of the racialized unwell.

Finally—but importantly—there is the question of why I use the word *Latinx*, a term that has not been universally agreed on by all of the artists whose work I examine in this study (nor by the scholars I cite). As a fairly new term, one the Pew Research Center reminds us has yet to be widely adopted (Noe-Bustamante, Mora, and López 2020), *Latinx* has its detractors, some of whom I find more persuasive than others.¹⁶

For this reason, it is important to me to specify that I do not use *Latinx* prescriptively or exclusively, and when describing artists and characters who use other identity markers (like Chicana or Latino), I use those. However, I am also inspired by the way Claudia Milian invokes the X as a methodological invitation: "What are we doing with the ethical and political uncertainty of X?" (2019, 7). Answering this question fully, of course, requires its own book (which Milian has already written), but in considering how this project might engage it, I am drawn to the words of Roy Pérez:

I really like the "x" signifier as a reclamation of all kinds of erasure. By using the "x" we expose erasure and refuse it at the same time. I'm a nerd, so for me it invokes the X-men, one of our most culturally visible and diverse narratives about xenophobia and fascism. It's also not lost on me that Black slaves, denied literacy and proper names, were compelled to sign "X" on their freedom papers. When we cross something out, the original remains doggedly just underneath. . . . All told, the "x" has a complex transnational history that is much more rich and full of resistance than a simple story of erasure suggests. I think it's great to be enamored with these linguistic possibilities—Spanish-speaking cultures are all about linguistic play and appropriation. That itself is a kind of freedom. (deOnís 2017, 86)

Pérez's invocation of the mutant superheroes the X-men, in particular, links the X to corporeal nonconformity. His invocation of something crossed out but still visible, remaining "doggedly just underneath," reminds me of how ideas about health and race layer on top of each other. Jonathan M. Metzl defines health as "a set of bodily practices whose ideological work is often rendered invisible by the assumption that it is a monolithic, universal good" (2010, 9). I imagine health as an X that leaves that ideological work partially visible, lurking doggedly just underneath. As a disability studies scholar, moreover, I am mindful of the ways in which nonnormative bodies of all kinds often disrupt gender binaries—or, rather, of the ways in which the gender binary and compulsory able-bodiedness are mutually reinforcing. For these reasons, the X feels right for *this* book, written in *this* moment, although I remain open to the evolution of language and to the possibility that it may not be right for everything I write in the future.

Overview

The chapters that follow cohere around close readings of aesthetic representations in order to foreground my argument that Latinx expressive culture can function as a public health intervention. I state this at the outset because, although I hope the pages that follow will be useful to readers from a wide range of disciplinary backgrounds, I also understand that close readings don't always hold the same interest for those who don't share my scholarly training in cultural criticism or literary studies. (I also recognize that readers who share my training may find some of the close readings too brief!) I use this method of close reading because, although I know that most of my

readers will be literary and cultural studies scholars, I also want to bring the artists and writers discussed here to the attention of others who share my interest in health justice, disability politics, and collective wellbeing. Because the chapters each examine a health-related theme as it is depicted in multiple texts, they can feel long. For this reason, I invite readers to skim, to bounce between sections, to pick and choose the analyses that most call to them. I have tried to write in such a way that makes this kind of fragmented reading possible—although, of course, I also welcome the reader who reads cover to cover. One of my goals is to see the texts I analyze here used more regularly in medical and public health training, and I hope that both my analyses and mode of organization (offering a series of short, stand-alone close readings instead of an extended analysis of a single text in each chapter) can help make that possible.

The first two chapters of *Radical Health* take a straightforward approach to the questions that guide this book, examining bodily conditions (HIV/AIDS and diabetes) that are overrepresented in conversations about Latinx communities and health. Chapter 1 examines Latinx cultural engagements with HIV/AIDS spanning the past three decades, from the 1990s until now, by Gil Cuadros, Jaime Cortez and Adela Vázquez, and Rafael Campo. Addressing the prevalence of HIV/AIDS in Latinx communities, these authors refute the myth that HIV/AIDS is a past-tense crisis and prompt us to reimagine the relationship between racial justice and health justice. Chapter 2 focuses on the representation of diabetes in the work of Sonia Sotomayor, Tato Laviera, Virginia Grise and Irma Mayorga, and ire'ne lara silva. I demonstrate how each of these artists refutes mainstream narratives about diabetes and represents the diabetic body as a site of love and political resistance.

The final two chapters take up an invitation by McRuer to imagine disability studies "more capaciously as an epistemological field that makes it possible to know about or intervene in any political or cultural issue" (2010, 164). They also move from an analysis of individual health conditions to a concern with public health. In these chapters, I examine how individualist approaches to health impact approaches to intimate partner violence and immigration policy, even though domestic abuse and immigration are rarely understood as health issues. Chapter 3 examines representations of gender-based and domestic violence in the work of Sonia Nazario, Alynda Mariposa Segarra (via their stage name, Hurray for the Riff Raff), Manuel Muñoz, Rigoberto González, and Angie Cruz to suggest alternate understandings of violence that enable more just solutions. Chapter 4 considers the call of public health scholar Viruell-Fuentes for further analysis of "the

health implications of immigration policies" (Viruell-Fuentes, Miranda, and Abdulrahim. 2012, 2102). It examines the health effects of contemporary immigration policy by addressing how Latinx writers (including Reyna Grande, Junot Díaz, Javier Zamora, and Karla Cornejo Villavicencio) have depicted the mental health effects of parent–child separations prompted by immigration.

Instead of ending each chapter with a conclusion that neatly ties together each argument, I end with a *remedio*. Here I use the Spanish word, often translated as *remedy* or *cure*, to think not only about the remedies that these texts imagine but also about the stakes of *remediation*, a word that is often used to refer to the reversal of damage but can also mean the translation from one medium to another. What does it mean, I ask throughout this book, to translate questions that are often seen as the purview of health professionals into an aesthetic medium? Why does it matter, in other words, that I have approached these public health concerns not through epidemiological investigation but through cultural criticism? Often my *remedios* take the form of meditating on the intellectual journey that brought me to a particular topic or the unanswered questions about it that continue to linger for me.

This is the especially the case with my final remedio, the book's short concluding chapter, in which I describe the personal experiences that brought me to this project. In this final meditation, I make explicit how my own social location—as a white, crip ciswoman who is often assumed (and for a long time assumed myself) to be nondisabled—has shaped my relationship to the texts I analyze and to the ideology of health. It is a common gesture among white scholars like myself who work in ethnic studies to invoke experiences demonstrating allyship, solidarity, and common cause (often filtered through shared social class background, shared neighborhoods, childhood friends, etc.). I believe such gestures are necessary, but I also believe that it is important for us to understand their limits. In this remedio, I wanted to tell a harder story, exploring how white supremacy and ableism have shaped the white liberalism in which I was raised—and which led me to both Latinx and disability studies. I have struggled with the question of where to place this story in the book, whether to start or end with it. In the end, I have opted to begin with the texts that have given me the concept of radical health, to center the artists and writers who give me faith that health is a concept worth reexamining, a concept that can be radically reimagined. Yet as I insist throughout this book that radical health can be envisioned from conditions of deep unwellness, I offer in the final chapter an account of my own attempt to do so.

NOTES

INTRODUCTION: RADICAL HEALTH/RADICAL UNWELLNESS

1 Mae M. Ngai argues that during the period following the Johnson-Reed Act of 1924, "restrictive immigration laws produced new categories of racial difference" (2004, 34-35). More specifically, she notes that during the late 1920s, the "actual and imagined association of Mexican with illegal immigration was part of an emergent Mexican 'race problem,' which also witnessed the application of Jim Crow segregation to Mexicans in the Southwest, especially in Texas, and, at the federal level, the creation of 'Mexican' as a separate racial category in the census" (36). In her history of the United States Border Patrol (established by the Johnson-Reed Act), Kelly Lytle Hernandez portrays immigration enforcement as "a site of racialization and inequity in the United States" (2010, 3). Building on these points, Natalia Molina's history of Mexican immigration to the United States between 1924 and 1965 bears the title *How Race Is Made in America*; she forcefully argues that "if we are to understand why we think about race and citizenship the way we do, we must thoroughly examine immigration laws and practices because they structure and lend meaning to these concepts" (2014, 11). Meanwhile, more recent works by Monica Muñoz Martinez and Beth Lew-Williams examine the role of racial violence in





- constructing particular groups of people as perpetually foreign; Martinez portrays anti-Mexican violence in early twentieth-century South Texas as "a past that bleeds into the present, a suppression that continues to shape our future" (2018, 10), while Lew-Williams (2018) elaborates how anti-Chinese violence gave rise to immigration restrictions like the 1882 Chinese Exclusion Act, even as such laws fomented further violence.
- 2 Bodymind is a term that I first encountered in the work of Margaret Price, who explains: "Because mental and physical processes not only affect each other but also give rise to each other—that is, because they tend to act as one, even though they are conventionally understood as two—it makes more sense to refer to them together, in a single term" (2015, 269). Expanding on Price's work, Sami Schalk highlights the term's particular utility for discussing experiences of racialized disability, noting that the term "can help highlight the relationship of nonphysical experiences of oppression—psychic stress—and overall wellbeing" (2018, 6).
- 3 Consider, for instance, Lennard Davis's famous and widely cited critique of the "kill-or-cure" ending of many disability narratives: "The alterity presented by disability is shocking to the liberal, ableist sensibility, and so narratives involving disability always yearn for the cure, the neutralizing of the disability" (2002, 99). The implication here is that a "yearn for the cure" always and only derives from ableist impulses.
- 4 Schalk and Kim critique the "cursory or comparative inclusion of race" (2020, 35) in much disability scholarship, a critique supported by the fact that the brief history recounted here is virtually unknown in disability studies. As one noteworthy example, the story of Isabel González is completely absent from the definitive history of disability and immigration, Douglas C. Baynton's *Defectives in the Land*, despite Baynton's emphasis on "the intersections between race and disability in immigration law" (2016, 6), despite the importance of the story to the construction of race in the twentieth-century United States, and despite the explicit role of visible physical difference in González's detention.
- 5 For more on the politics of work and care as related to both welfare reform and the ADA, see Frye 2016 and J. B. Kim 2021.
- 6 Laura Briggs writes: "The welfare reform discussion that began under Reagan provided the cultural cover to initiate this massive economic restructuring, and it involved a deliberate, policy-driven shift in political power away from unions, people of color, and women, and to corporations and the wealthy. It was mobilized in ways that particularly affected women and people of color and traded on negative stereotypes of those groups to effect its changes while not seeming callous. The poor, it told us, were responsible for their own poverty through their bad choices" (2017, 73–74).
- 7 For a report of Chaffetz's comments, see Shelbourne 2017. For an analysis of how the cost of a new iPhone in 2017 actually compared to the average cost

- of health care at that time (and, thus, for a full account of the dishonesty and callousness of Chaffetz's remarks), see Ingraham 2017.
- 8 On this point, Anna Kirkland and Diana Bowman coedited a special issue of the *Journal of Health Policy, Politics and Law*, entitled "The Law and Politics of Workplace Wellness," inspired by the ACA's changes to rules governing workplace wellness programs, notably its creation of an exception to the nondiscrimination provisions of the Health Insurance Portability and Accountability Act (HIPAA). This special issue, and particularly Kirkland's contribution, is not extensively cited here but catalyzed my thinking as I began to conceptualize this book. See Kirkland 2014.
- 9 Gordon (2013) cites the law's reliance on employer-based insurance and states' willingness to expand Medicaid, also major flaws.
- The anthropologist Jonathan Xavier Inda terms this the "necropolitics of uncare" (2020, 700). Inda develops the term through an analysis of preventable deaths, often resulting from the withholding of medical care, of immigrants in US Immigration and Customs Enforcement (ICE) detention; he argues that such immigrants "are allowed to perish in the name of protecting and nurturing the life of the national population—making it clear that migrant lives do not matter" (703). Although the situations that inspire Inda's term are particularly horrific, I would argue that the term also applies to more mundane, routinized instances in which racialized populations are either outright denied treatment or given substandard care.
- 11 The concept *healthism* is also usefully developed in the work of Julie Guthman (2011) and Anna Kirkland (2011).
- 12 I include addiction on this list despite studies showing that drug use is more prevalent in white communities than in communities of color, and despite the concentration of a widely publicized opioid addiction crisis in rural white communities as I write, because of evidence suggesting that addiction is more likely to be treated as a health problem for white people experiencing it and more likely to be criminalized for people of color experiencing it. In this sense, even if addiction is not more *prevalent* in communities of color, its effects are still more devastating.
- 13 In this regard, it is useful to contrast Barack and Michelle Obama to Bill and Hillary Clinton, who spearheaded an effort during the 1990s to create a national health care system that failed spectacularly. Bill Clinton (who famously became a vegan after leaving the presidency) was often photographed eating hamburgers on the campaign trail, and his dietary habits were a target of satire. Hillary Clinton, appointed to chair the task force that created the Clinton health care plan, was skewered by the right for overreaching what was considered to be the role of the First Lady (devotion to a charitable cause without ambition to create policy). For more substantial analysis of Michelle Obama's Let's Move! campaign, see Cowing 2020 and Kulbaga and Spencer 2017.



- 14 Bonilla-Silva's term for this racial ideology is *color-blind racism*. Although I find Bonilla-Silva's insights absolutely indispensable, I choose not to employ this term in order to heed the warnings of disability scholars about the problems with using bodily and sensory impairments as metaphors for social problems.
- 15 I am inspired by scholars who have expanded Charon's approach. Notably, Phillip J. Barrish proposes that "we who study intersections of literature and medicine should devote more sustained attention to literary engagements with health care as a system: a complex, often fragmented set of financial models, institutions, government policies, and personnel whose roles range well beyond patient and care provider" (2016, 106). Olivia Banner proposes reading not for the illness narrative but for "the politics of illness" (2016, 32), advocating a "move away from the current emphasis on individuals learning to behave better and instead toward individuals understanding how institutions and structures condition that behavior" (45). And Charon's colleagues at Columbia, Yoshiko Iwai, Zahra H. Khan, and Sayantani DasGupta, propose a revision of narrative medicine as abolition medicine, which aims "to renarrate and re-envision justice, healing, activism, and collectivity" (2020, 159).
- 16 For instance, I am not interested in the argument that *Latinx* constitutes a form of linguistic imperialism simply because it seeks to subvert the grammatical gender of the Spanish language; as a teacher, I aspire to a pedagogy that eschews valuations of "correct" grammar in any language, so it doesn't make sense to import such valuations into my scholarship. However, I do have some affinity for the argument (made by Richard T. Rodríguez and others) that *Latinx*, which arises out of a desire to include nonbinary people who don't identify with either the *A* or the *O* in *Latina/o*, actually has the opposite effect when used "for the express purpose of shorthand (i.e., making things easier with the singular X rather than form an unwieldy term consisting of too many pronouns)" (Rodríguez 2017, 205–6).

1. UNPROTECTED TEXTS

1 This is not to argue that people should not take precautions against the transmission of STDs. It is to acknowledge that "un/protected" sex is a category that shifts in meaning with advances in knowledge about HIV transmission and the availability of new drug therapies, especially pre-exposure prophylaxis (PrEP) drugs. Condom use, serosorting, oral and manual sex, preventative drugs, and strategic positioning are all HIV prevention strategies with varying degrees of availability, cost, effectiveness, and risk—and given the vagueness of the term, all could be described as "protected" or "unprotected." My point, then, is that attaching stigma and shame to "unprotected" sex, especially when the meaning of the term is so imprecise, is not an effective public health measure. As Paula A. Treichler argues: "AIDS