This book is and is not for the academy. It is research based and interdisciplinary, and thus, as a scholar, I anticipate and hope that it has influence and value among my colleagues. At the same time, I want this book to have value and utility outside the academy; for Black people, especially Black disabled people, to understand our history of Black disability politics in order to claim it, learn from it, and take it more explicitly into our multiple kinds of justice work in the world. As a result, this is not a conclusion so much as the final words before a pause in the conversation, a pause where people will read or listen to this work and then pick up the conversation in their own fields, organizations, and cultural spaces. I hope that you will talk, post, tweet, critique, write back, and engage others on these ideas to further research and enact Black disability politics.

To write this brief nonconclusion, I use a framework I first experienced as an undergraduate student in the classes of Dr. Kathy McMahon-Klosterman, the first person to introduce me to disability studies, when I was nineteen. Dr. McMahon-Klosterman always had us write reflections on our final projects by answering the questions *What? So what? Now what?* That is: What did you do? Why does it matter? What needs to happen next to further this work? I am and always will be grateful for what Dr. McMahon-Klosterman taught me about integrating one’s teaching, scholarship, and activism.
What?

This book has explored how Black people have engaged with disability as a political issue through exploration and analysis of the work of the Black Panther Party, the National Black Women’s Health Project, and twenty-first-century Black disabled cultural workers. I have argued that Black people’s engagement with disability politics has been overlooked, ignored, and misrecognized because it doesn’t always look like the disability political work of the white-dominated mainstream disability rights movement. However, there is unquestionably a legacy of Black people, disabled and nondisabled, working for the liberation of disabled people in direct relationship to the fights against white supremacy and capitalism. In analyzing the political work of Black cultural workers on disability issues, I identified four common qualities of Black disability politics: they are intersectional but race centered, not necessarily based in disability identity, contextualized and historicized, and holistic. These qualities are useful both in identifying previous or existing Black cultural work that we ought to consider Black disability politics and in creating new Black disability political work in the present and future. These qualities remain relatively consistent across the differing eras and groups I’ve explored; however, importantly, in twenty-first-century Black disability politics, disability is much more explicitly engaged in intersectional approaches and is far more likely to be claimed as an identity by Black cultural workers, though identity claims are not necessary for doing Black disability political work.

So What?

Why does tracing a history of Black disability politics and articulating common qualities matter? First and foremost, this work matters because Black disabled people matter. Black disabled people have a social and political history that we must understand in order to create collective liberation. For scholars, this work demonstrates that our approach to identifying and studying disability and disability politics needs to be rooted in the way disability is understood within a particular community and historical moment. Current definitions of disability and understandings of what constitutes disability politics are far too narrow and based primarily on white experiences and understandings of disability. Scholars of Black people, Black history, and Black culture must look for how Black communities have addressed issues of disability, health, illness, disease, and wellness without depending
on medical or legal frameworks. For activists and other cultural workers, my work here matters because it demonstrates an activist legacy that we can not only claim but learn from as well. Throughout I have not merely recounted this legacy, but I have also critiqued its missteps and failures, presenting ideas as to how we might take up the useful tactics and learn from the errors that often unwittingly perpetuated ableism. If nothing else, researching and writing this book has made clear to me that looking lovingly yet critically at the work of our political ancestors is the only way to ensure that our work in the present is effective and lasting. We get better only if we are willing to admit where we have gone wrong, as individuals and as collectives, and if we then truly integrate the lessons we have learned into future work.

Now What?

What happens next with this work? For scholars, I hope more of us can identify and analyze Black disability politics in a range of Black cultural work from activism and organizing to art and literature, including more archival and oral history work. In doing such scholarship, I also would like to see more academics try harder to create accessible ways (financially and intellectually) for people outside of the academy to read, understand, and use our work. I do not believe in knowledge for the sake of knowledge. We live in an era where information can be rapidly shared. And while the process of research might be slow, the spread of the knowledge gained from that research must occur in many ways outside of ivory tower lecture halls, paywalled journals, and inaccessibly written four-hundred-page books. While these methods for disseminating information have some value, we must all fight to ensure they are not the only places where we share what we have learned.

For activists and other cultural workers, the next step is to take this knowledge about Black disability politics and share it, talk about it, follow the lead of the living activists I interviewed, and incorporate Black disability politics into your work and your life. This means moving toward a political model that fully recognizes the mutually constitutive nature of disability, race, gender, sexuality, and class. This cannot be in name only. It cannot just mean saying the word disability sometimes. The work has to transform. We must make activism and politics accessible. We must center those most marginalized and make sure all of our people get free, each and every one of us. We must reject models that move at an unsustainable pace, burn people out, and harm, even traumatize, people. The skill set of accessible
organizing is needed in all activist work, even in work that is not explicitly about disability or health, because disabled, sick, and chronically ill people are involved in all non-disability-explicit work, because they, too, are Black people, Muslim people, poor people, sexual assault survivors, immigrants, and so on. Disabled people are increasingly leaders, demonstrating how to organize and create political and social change in our present moment. We must claim that, recognize that, and do everything we can to ensure the participation and leadership of multiply marginalized disabled people.

Concluding Thoughts during the Uprisings of 2020

I am writing these concluding thoughts in the midst of a global pandemic and what I’ve begun to call “the uprisings.” Everything is surreal. Everything feels urgent. Nothing makes sense and yet … I still feel compelled to write, to finish this book.

When the pandemic began to shut things down in the United States in March 2020, I watched my disabled friends and colleagues offer immense knowledge to the nondisabled world on how to move events and meetings to virtual platforms, how to find and wear masks, how to keep mental wellness intact during long periods of isolation, how to make one’s own hand sanitizer, how to connect with others when one could not touch people or leave one’s home. Disabled people led the way in showing folks how to care for their full bodyminds through a global pandemic. Then the uprisings began. And again, knowledge about organizing from a variety of bodyminds and spaces emerged from disability justice communities.

Here in Madison I joined Freedom Inc., a Black and Southeast Asian queer feminist activist and advocacy organization for which I am a board member, for a large march on May 30, 2020. Alix Shabazz, a Black disabled queer woman organizer, asked me to be a “care bear” for the event, someone who distributed food, water, and, at that moment, masks, gloves, and hand sanitizer to protesters to help keep everyone safe. Alix later told me that she learned about care roles in protests from disability justice organizers. Several of us acting as care bears, security, and medics communicated in a group chat all day. That night some community members continued their own protest after the march, and property was damaged downtown. Madison police showed up in riot gear, spraying gas at protesters and bystanders in the way, creating chaos, harm, and trauma. The city issued a curfew, and the uprisings officially arrived in Madison.
Some of us in the original security and care network for the march continued to work together privately, slowly, organically, growing our network to include trusted friends. As local organizations and individuals planned protests and marches day after day, our network of over thirty people worked in the background to ensure as much safety and care as possible at every event. What amazed me about this organically formed network, this organized nonorganization, was the incredible leadership and participation by disabled people, particularly Black disabled people. Some of us could not risk being out in public with large crowds, so instead we stayed up late monitoring livestreams from protesters on social media and using information gathered from the streams to communicate with our people on the ground about where to send medics, where to send supplies, and where to avoid the police and National Guard. Others would listen to police scanners, privately fundraise, or make runs to grocery stores and pharmacies for supplies. For a while, it felt as if the state was explicitly at war with us, and we needed every person, every skill, to help our people stay safe as they expressed their righteous anger and demanded radical change: Defund the police. Abolish prisons. Forgive student loans. Put a moratorium on rent and evictions. Value people over property. All echoes of the demands of the Black Panther Party decades before us.

Days later, the curfew was lifted, and the police and National Guard reduced their visible militarized presence downtown while still leaving snipers on buildings, undercover officers in our marches, and tanks on the edges of town, ready to mobilize at a moment’s notice. At that point, some of us chose to be on the ground but in our cars only, participating in caravans that shut down major intersections and highways and at other times serving as physical protection for marches by driving in front of or behind the group. There were so many roles for a variety of bodymind and access needs, and each of these roles was valued among my network. This was my first time doing so much on-the-ground protesting and organizing. I had just finished writing everything for this book except the conclusion, and I found myself constantly identifying Black disability politics in our work even as they were rarely named as such. Now, however, I would like to frame them as disability political practices here and document the crip brilliance that made the uprisings as significant and sustained as they were here in Madison.

As I drove at the front of one march, I thought about how keeping a slow pace with lots of stops for people to rest is not only a safety practice to keep the group together but also a disability justice practice to make marches more
accessible and to refuse to leave behind those who move at a different pace than the majority. At multiple protests I distributed free water, food, face masks, sunscreen, and/or bug spray from a collapsible wagon I now just keep in my car at all times. This was in one sense an adaptive access practice for my own bodymind because I knew I couldn’t carry very much at once, so the wagon allowed me to be more effective in distributing these items through a large crowd without hurting myself. More largely, though, I often thought about the holistic nature of Black disability politics and the way providing food, water, face masks, and other supplies directly connects to the need to practice holistic care for people at protests, especially when folks are new to such events or were perhaps not informed or aware of how long one action can last. We also had medics on-site, and one member of the group carried essential oils and tinctures to events for folks needing help calming down or grounding when things got hectic or scary. When we care for everyone’s bodyminds, more people are able to participate for longer periods of time—with more energy and joy. Finally, in my network of organizers, I witnessed people name their self-care practices and access needs openly to the group, such as “I need to take today off” or “I can come to the march, but I need someone to be my buddy and stay next to me” or “I’m running low on energy, can someone let me ride in a car for a while?” While not everyone openly identified as disabled, I was regularly impressed by not only the naming of and response to these needs but the active celebration and encouragement of these disability justice access practices. Once I was going to be late to an event because I couldn’t move my therapy appointment. I said so, and not only did folks adjust around my timing without question, but people also responded in the group text with comments like “Yay therapy!” This kind of atmosphere allowed me to bring my full self in whatever capacity I had at the moment into the work.

I rarely heard people use the word disability to help explain or politicize these various practices, which is why I want to frame them in this way here. I believe there is value in us naming these as disability political practices because doing so makes care work (for self and others) political and valuable in a world that often feminizes and thus devalues it. Further, if we create a Black liberation movement that understands Black disability politics to be essential, then these practices would be nonnegotiable for all organizing, activism, and protest work, fighting legacies of burnout/overwork culture that allows ableism to flourish. By explicitly naming practices already occurring in many Black movement spaces as disability politics, we recognize the role and value of disabled people in Black liberation work. It is time for
all Black people to claim Black disability politics as one of many tools we need in the fight for our freedom.

Right now, admittedly, it is hard to imagine what the future looks like. The days blend together, and the pandemic rages on, seemingly unabated. Black people are dying at disproportionate rates from COVID-19, and for those who survive, it will be years before we truly understand the long-term disabling impact of the virus on our communities. Black disabled people deserve to exist now and well into the future, and that can occur only if all Black people (and our allies) follow the lead of multiply marginalized disabled people who have watched—from their beds, from their homes, from the bus, from hospital rooms—how nondisabled people operate, pretending that these bodyminds of ours will last forever, that this earth will last forever, as if we do not need to slow down, to support each other, to account for—let alone learn from—those we have historically isolated, ignored, and let die. Disabled people know how to survive this. Our knowledge is part of how we as a collective not only make it to the other side but also build a new world that is more capable of responding with care for all of us, not just some of us. What I see emerging in this moment is a time for Black people to embrace disability politics explicitly and consistently, a moment when following the lead of Black disabled people and other disabled people of color who have survived and organized within hurricanes, days without electricity, wildfires, smoke hazards, tear gassing, pepper spraying, COVID-19, and more is our best hope. When this ends—and I do hope this particular crisis ends soon—we cannot go back to things as they were. Based on both my research and my lived experience during these uprisings, I believe the future of the Black liberation movement and its longevity depend on its ability to incorporate Black disability politics. This cannot be a politics only held and enacted by disabled people or when disabled people are visible at a protest. It must always be a part of planning and executing this work. Always. I hope that in some ways this book can contribute to such changes. Thank you for the gift of your time and attention. Thank you for caring enough to make it to the end. May you take something away to help make a better world.

—June 2020, Madison, WI