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# FEMINIST, QUEER, CRIP

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# Introduction

## *Imagined Futures*

I dream of more inclusive spaces.

—Kavitha Koshy, "Feels Like Carving Bone"

I HAVE NEVER CONSULTED a seer or psychic; I have never asked a fortune-teller for her crystal ball. No one has searched my tea leaves for answers or my stars for omens, and my palms remain unread. But people have been telling my future for years. Of fortune cookies and tarot cards they have no need: my wheelchair, burn scars, and gnarled hands apparently tell them all they need to know. My future is written on my body.

In 1995, six months after the fire, my doctor suggested that my thoughts of graduate school were premature, if not misguided. He felt that I would need to spend the next three or four years living at home, under my parents' care, and only then would it be appropriate to think about starting school. His tone made it clear, however, that he thought graduate school would remain out of reach; it was simply not in my future. What my future did hold, according to my rehabilitation psychologist and my recreation therapist, was long-term psychological therapy. My friends were likely to abandon me, alcoholism and drug addiction loomed on my horizon, and I needed to prepare myself for the futures of pain and isolation brought on by disability. Fellow rehab patients, most of whom were elderly people recovering from strokes or broken hips, saw equally bleak horizons before me. One stopped me in the hallway to recommend suicide, explaining that life in a wheelchair was not a life worth living (his son, he noted offhandedly, knew to "let him go" if he was eventually unable to walk).

My future prospects did not improve much after leaving the rehabilitation facility, at least not according to strangers I encountered, and continue to encounter, out in the world. A common response is for people to assume they know my needs better

than I do, going so far as to question my judgment when I refuse their offers of help. They can apparently see into my immediate future, forecasting an inability to perform specific tasks and predicting the accidents and additional injuries that will result. Or, taking a longer view, they imagine a future that is both banal and pathetic: rather than involving dramatic falls from my wheelchair, their visions assume a future of relentless pain, isolation, and bitterness, a representation that leads them to bless me, pity me, or refuse to see me altogether. Although I may believe I am leading an engaging and satisfying life, they can see clearly the grim future that awaits me: with no hope of a cure in sight, my future cannot be anything but bleak. Not even the ivory tower of academia protected me from these dismal projections of my future: once I made it to graduate school, I had a professor reject a paper proposal about cultural approaches to disability; she cast the topic as inappropriate because insufficiently academic. As I prepared to leave her office, she patted me on the arm and urged me to “heal,” suggesting that my desire to study disability resulted not from intellectual curiosity but from a displaced need for therapy and recovery. My future, she felt, should be spent not researching disability but overcoming it.

These grim imagined futures, these suggestions that a better life would of necessity require the absence of impairment, have not gone unchallenged. My friends, family, and colleagues have consistently conjured other futures for me, refusing to accept ableist suggestions that disability is a fate worse than death or that disability prohibits a full life. Those who have been most vocal in imagining my future as ripe with opportunities have been other disabled people, who are themselves resisting negative interpretations of their futures. They tell stories of lives lived fully, and my future, according to them, involves not isolation and pathos but community and possibility: I could write books, teach, travel, love and be loved; I might raise children or become a community organizer or make art; I could engage in activist struggles for the rights of disabled people or get involved in other movements for social justice.

At first glance, these contradictory imagined futures have nothing in common: the first casts disability as pitiable misfortune, a tragedy that effectively prevents one from leading a good life, while the second refuses such inevitability, positioning ableism—not disability—as the obstacle to a good life. What these two representations of the future share, however, is a strong link to the present. How one understands disability in the present determines how one imagines disability in the future; one’s assumptions about the experience of disability create one’s conception of a better future.

If disability is conceptualized as a terrible unending tragedy, then any future that includes disability can only be a future to avoid. A better future, in other words, is one that excludes disability and disabled bodies; indeed, it is the very *absence* of disability that signals this better future. The *presence* of disability, then, signals something else: a future that bears too many traces of the ills of the present to be desirable. In this framework, a future with disability is a future no one wants, and the figure of the disabled person, especially the disabled fetus or child, becomes the symbol of this undesired

future. As James Watson—a geneticist involved in the discovery of DNA and the development of the Human Genome Project—puts it, “We already accept that most couples don’t want a Down child. You would have to be crazy to say you wanted one, because that child has no future.” Although Watson is infamous for making claims about who should and shouldn’t inhabit the world, he’s not alone in expressing this kind of sentiment.<sup>2</sup> Watson’s version simply makes clear some of the assumptions underlying this discourse, and they are assumptions that cut to the heart of this project. The first is that disability is seen as the sign of no future, or at least of no good future. The second, and related, assumption is that we all agree; not only do we accept that couples don’t want a child with Down syndrome, we know that anyone who feels otherwise is “crazy.” To want a disabled child, to desire or even to accept disability in this way, is to be disordered, unbalanced, sick. “We” all know this, and there is no room for “you” to think differently.

It is this presumption of agreement, this belief that we all desire the same futures, that I take up in this book. I am particularly interested in uncovering the ways the disabled body is put to use in these future visions, attending to both metaphorical and “corporeal presence and absence.” I argue that disability is disavowed in these futures in two ways: first, the value of a future that includes disabled people goes unrecognized, while the value of a disability-free future is seen as self-evident; and second, the political nature of disability, namely its position as a category to be contested and debated, goes unacknowledged. The second failure of recognition makes possible the first; casting disability as monolithic fact of the body, as beyond the realm of the political and therefore beyond the realm of debate or dissent, makes it impossible to imagine disability and disability futures differently. Challenging the rhetoric of naturalness and inevitability that underlies these discussions, I argue that decisions about the future of disability and disabled people are political decisions and should be recognized and treated as such. 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. Thus, in tracing these two failures of recognition—the disavowal of disability from “our” futures—I imagine futures otherwise, arguing for a crippled politics of access and engagement based on the work of disability activists and theorists.

What *Feminist, Queer, Crip* offers is a politics of crip futurity, an insistence on thinking these imagined futures—and hence, these lived presents—differently. Throughout the course of the book, I hold on to an idea of politics as a framework for thinking through how to get “elsewhere,” to other ways of being that might be more just and sustainable. In imagining more accessible futures, I am yearning for an elsewhere—and, perhaps, an “elsewhen”—in which disability is understood otherwise: as political, as valuable, as integral.

Before going any further, I admit to treading tricky ground here. “A future with disability is a future no one wants,” while I find it absolutely essential to dismantle



the purported self-evidence of that claim, I can't deny that there is truth to it. Not only is there abstract truth to it, there's personal, embodied truth: it is a sentiment I myself hold. As much joy as I find in communities of disabled people, and as much as I value my experiences as a disabled person, I am not interested in becoming more disabled than I already am. I realize that position is itself marked by an ableist failure of imagination, but I can't deny holding it. Nor am I opposed to prenatal care and public health initiatives aimed at preventing illness and impairment, and futures in which the majority of people continue to lack access to such basic needs are not futures I want.<sup>5</sup> But there is a difference between denying necessary health care, condoning dangerous working conditions, or ignoring public health concerns (thereby causing illness and impairment) and recognizing illness and disability as part of what makes us human.<sup>6</sup> While definitively mapping that difference is beyond the scope of this book—and, I would argue, neither fully possible nor desirable—sketching out some of the potential differences is exactly the work we need to be doing.

### Defining Disability: A Political/Relational Model

The meaning of disability, like the meaning of illness, is presumed to be self-evident; we all know it when we see it. But the meanings of illness and disability are not nearly so fixed or monolithic; multiple understandings of disability exist. Like other disability studies scholars, I am critical of the medical model of disability, but I am equally wary of a complete rejection of medical intervention. In the pages that follow, I offer a hybrid political/relational model of disability, one that builds on social and minority model frameworks but reads them through feminist and queer critiques of identity. My concern with imagining disability futures differently frames my overview of each model; thinking about the kinds of futures imagined or implicit in each definition provides a useful lens for examining the assumptions and implications of these frameworks.

Despite the rise of disability studies in the United States, and decades of disability rights activism, disability continues to be seen primarily as a personal problem afflicting individual people, a problem best solved through strength of character and resolve. This individual model of disability is embodied in the disability simulation exercises that are a favored activity during "disability awareness" and diversity events on college campuses (including, in years past, my own). For these kinds of events, students are asked to spend a few hours using a wheelchair or wearing a blindfold so that they can "understand" what it means to be blind or mobility-impaired.<sup>7</sup> Not only do these kinds of exercises focus on the alleged failures and hardships of disabled bodies (an inability to see, an inability to walk), they also present disability as a knowable fact of the body. There is no accounting for how a disabled person's response to impairment shifts over time or by context, or how the nature of one's impairment changes, or, especially, how one's experience of disability is affected by one's culture and environment. Wearing a blindfold to "experience blindness" is going to do little to teach someone about ableism, for example, and suggests that the only thing there is to learn about

blindness is what it feels like to move around in the dark. The meaning of blindness, in other words, is completely encapsulated in the experience of wearing a blindfold; there is simply nothing else to discuss. Although these kinds of exercises are intended to reduce fears and misperceptions about disabled people, the voices and experiences of disabled people are absent. Absent also are discussions about disability rights and social justice; disability is depoliticized, presented more as nature than culture. As Tobin Siebers notes, these are exercises in "personal imagination" rather than "cultural imagination," and a limited imagination at that.<sup>8</sup>

This individual model of disability is very closely aligned with what is commonly termed the medical model of disability; both form the framework for dominant understandings of disability and disabled people. The medical model of disability frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms. In this framework, the proper approach to disability is to "treat" the condition and the person with the condition rather than "treating" the social processes and policies that constrict disabled people's lives.<sup>9</sup> Although this framing of disability is called the "medical" model, it's important to note that its use isn't limited to doctors and other service providers; what characterizes the medical model isn't the position of the person (or institution) using it, but the positioning of disability as an exclusively medical problem and, especially, the conceptualization of such positioning as both objective fact and common sense.<sup>10</sup>

Indeed, some of the most passionate defenses of the medical model of disability occur outside the hospital or clinic. Literary critic Denis Dutton exemplifies this pattern of thought, condemning a writing manual for its attempt to describe disability in social rather than medical terms. Dutton refuses the need for such attention to disability language, countering that "*it is the medical condition that is the problem, not the words that describe it.*"<sup>11</sup> Because disability is a purely medical problem, Dutton finds no need to engage with disability as a category of analysis; concepts such as able-bodiedness, healthiness, and the normal body, or conditions such as "blindness, wheelchairs, polio, and cretinism" do not require or merit critical attention for they are merely facts of life.<sup>12</sup> For Dutton, disability is a self-evident, unchanging, and purely medical phenomenon, and the meanings, histories, and implications of "cretinism," for example, are not available for debate or dissent.

Thus, in both the individual and medical models, disability is cast as a problematic characteristic inherent in particular bodies and minds. Solving the problem of disability, then, means correcting, normalizing, or eliminating the pathological individual, rendering a medical approach to disability the only appropriate approach. The future of disability is understood more in terms of medical research, individual treatments, and familial assistance than increased social supports or widespread social change.

Disability studies scholars and disability activists, however, refute the premises of the medical/individual framework. Rather than casting disability as a natural, self-evident sign of pathology, we recast disability in social terms. The category of "disabled"

can only be understood in relation to “able-bodied” or “able-minded,” a binary in which each term forms the borders of the other. As Rosemarie Garland-Thomson explains, this hierarchical division of bodies and minds is then used to “legitimate” an unequal distribution of resources, status, and power within a biased social and architectural environment.<sup>39</sup> In this construction, disability is seen less as an objective fact of the body or mind and more as a product of social relations.

Thus, the definitional shift away from the medical/individual model makes room for new understandings of how best to solve the “problem” of disability. In the alternative perspective, which I call the political/relational model, the problem of disability no longer resides in the minds or bodies of individuals but in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being. For example, under the medical/individual model, wheelchair users suffer from impairments that restrict their mobility. These impairments are best addressed through medical interventions and cures; failing that, individuals must make the best of a bad situation, relying on friends and family members to negotiate inaccessible spaces for them. Under a political/relational model of disability, however, the problem of disability is located in inaccessible buildings, discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies. The problem of disability is solved not through medical intervention or surgical normalization but through social change and political transformation.

This is not to say that medical intervention has no place in my political/relational model. By my reckoning, the political/relational model neither opposes nor valorizes medical intervention; rather than simply take such intervention for granted, it recognizes instead that medical representations, diagnoses, and treatments of bodily variation are imbued with ideological biases about what constitutes normalcy and deviance. In so doing, it recognizes the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people.<sup>40</sup> I want to make room for people to acknowledge—even mourn—a change in form or function while also acknowledging that such changes cannot be understood apart from the context in which they occur.

In juxtaposing a medical model with a political one, I am not suggesting that the medical model is not itself political. On the contrary, I am arguing for increased recognition of the political nature of a medical framing of disability. As Jim Swan argues, recognizing that a medical model is political allows for important questions about health care and social justice: “How good is the care? Who has access to it? For how long? Do they have choices? Who pays for it?”<sup>41</sup> Swan’s questions remind us that medical framings of disability are embedded in economic realities and relations, and the current furor over health care reform underscores the political nature of these questions. Moreover, as scholars of feminist science studies, reproductive justice, and public health continue to make clear, medical beliefs and practices are not immune to or separate from cultural practices and ideologies. Thus, in offering a political/relational

model of disability, I am arguing not so much for a rejection of medical approaches to disability as for a renewed interrogation of them. Insisting upon the political dimension of disability includes thinking through the assumptions of medical/individual models, seeing the whole terrain of “disability” as up for debate.<sup>42</sup>

My framing of disability as political/relational is intended as a friendly departure from the more common social model of disability. Like Margrit Shildrick and Janet Price, my intent is to “demand an unsettling of its certainties, of the fixed identities of which it is bound up” and to pluralize the ways we understand bodily instability.<sup>43</sup> Although both the social and political/relational models share a critique of the medical model, the social model often relies on a distinction between impairment and disability that I don’t find useful. In that framework, impairment refers to any physical or mental limitation, while disability signals the social exclusions based on, and social meanings attributed to, that impairment.<sup>44</sup> People with impairments are disabled by their environments; or, to put it differently, impairments aren’t disabling, social and architectural barriers are. Although I agree that we need to attend to the social, asserting a sharp divide between impairment and disability fails to recognize that *both* impairment and disability are social; simply trying to determine what constitutes impairment makes clear that impairment doesn’t exist apart from social meanings and understandings. Susan Wendell illustrates this problem when she queries how far one must be able to walk to be considered able-bodied; the answer to that question, she explains, has much to do with the economic and geographic context in which it is addressed.<sup>45</sup> What we understand as impairing conditions—socially, physically, mentally, or otherwise—shifts across time and place, and presenting impairment as purely physical obscures the effects of such shifts. As feminist theorists have long noted, there is no mention of “the” body that is not a further articulation of a very particular body.<sup>46</sup>

At the same time, the social model with its impairment/disability distinction erases the lived realities of impairment; in its well-intentioned focus on the disabling effects of society, it overlooks the often-disabling effects of our bodies. People with chronic illness, pain, and fatigue have been among the most critical of this aspect of the social model, rightly noting that social and structural changes will do little to make one’s joints stop aching or to alleviate back pain. Nor will changes in architecture and attitude heal diabetes or cancer or fatigue. Focusing exclusively on disabling barriers, as a strict social model seems to do, renders pain and fatigue irrelevant to the project of disability politics.<sup>47</sup>

As a result, the social model can marginalize those disabled people who are interested in medical interventions or cures. In a complete reversal of the individual/medical model, which imagines individual cure as the desired future for disability, a strict social model completely casts cure out of our imagined futures; cure becomes the future no self-respecting disability activist or scholar wants. In other words, because we are so often confronted with the medical framing of disability as unending burden, or as a permanent drag on one’s quality of life, disability rights activists and scholars



tend to deny our own feelings of pain or depression; admitting to struggling with our impairments or to wanting a cure for them is seen as accepting the very framings we are fighting against, giving fodder to the enemy, so to speak. But by positioning ourselves only in opposition to the futures imagined through the medical model, and shutting down communication and critique around vital issues, we limit the discourses at our disposal. As Liz Crow warns, in refusing to acknowledge pain, fatigue, or depression, “our collective ability to conceive of, and achieve, a world which does not disable is diminished.”<sup>22</sup>

Finally, drawing a hard line between impairment and disability, and having this distinction serve as the foundation for theorizing disability, makes it difficult to explore the ways in which notions of disability and able-bodiedness affect everyone, not just people with impairments.<sup>23</sup> Anxiety about aging, for example, can be seen as a symptom of compulsory able-bodiedness/able-mindedness, as can attempts to “treat” children who are slightly shorter than average with growth hormones; in neither case are the people involved necessarily disabled, but they are certainly affected by cultural ideals of normalcy and ideal form and function. Or, to take this idea in a different direction, friends and family members of disabled people are often affected by ableist attitudes and barriers, even if they are not themselves disabled. Their social lives may shrink, for example, because others are uncomfortable or embarrassed by their stories of illness and adaptation, or friends may feel guilty inviting them to inaccessible houses; difficulty accessing reliable and affordable attendant care or finding appropriate housing certainly affects entire families, not only the disabled person herself or himself. Moreover, not only does disability exist in relation to able-bodiedness/able-mindedness, such that disabled and abled form a constitutive binary, but also, to move to a different register of analysis, disability is experienced in and through relationships; it does not occur in isolation. My choice of a *relational* model of disability is intended to speak to this reality.

Similarly, my articulation of a *political* framing of disability is a direct refusal of the widespread depoliticization of disability. Dutton’s medicalized description of disability assumes that “cretinism” is a natural category, derived purely from objective medical study and irrelevant to discussions of politics or prejudice; proclaiming the naturalness of disability, he goes on to ridicule attempts to discuss disability in terms of language or identification.<sup>24</sup> By asserting that we cannot (or should not) resignify disability identities and categories, refusing to recognize the impact disability rhetoric and terminology might have on understandings of disability (and thus on the lives of disabled people), and insisting that medical approaches to disability are completely objective and devoid of prejudice or cultural bias, Dutton completely removes disability from the realm of the political. In doing so, he forecloses on the possibility of understanding disability differently; divorcing disability and disabled people from understandings of the political prohibits incorporating disability into programs of social change and transformation or, in other words,

into visions of a better future. Once disability has been placed solely in the medical framework, and both disability and the medical world are portrayed as apolitical, then disability has no place in radical politics or social movements—except as a problem to be eradicated.

A political/relational model of disability, on the other hand, makes room for more activist responses, seeing “disability” as a potential site for collective reimagining. Under this kind of framework, “disability awareness” simulations can be reframed to focus less on the individual experience of disability—or imagined experience of disability—and more on the political experience of disablement. For example, rather than placing nondisabled students in wheelchairs, the Santa Barbara-based organization People in Search of Safe and Accessible Restrooms (PISSAR) places them in bathrooms, armed with measuring tapes and clipboards, to track the failures and omissions of the built environment. As my fellow restroom revolutionaries explain in our manifesto, “This switch in focus from the inability of the body to the inaccessibility of the space makes room for activism and change in ways that ‘awareness exercises’ may not.”<sup>25</sup> In creating and disseminating a “restroom checklist,” PISSAR imagines a future of disability activism, one with disability rights activists demanding accessible spaces; contrast that approach with the simulation exercises, in which “awareness” is the future goal, rather than structural or systemic change.

In reading disability futures and imagined disability through a political/relational model, I situate disability squarely within the realm of the political. My goal is to contextualize, historically and politically, the meanings typically attributed to disability, thereby positioning “disability” as a set of practices and associations that can be critiqued, contested, and transformed. Integral to this project is an awareness that ableist discourses circulate widely, and not only in sites marked explicitly as about disability; thus, thinking about disability as political necessitates exploring everything from reproductive practices to environmental philosophy, from bathroom activism to cyberculture. I am influenced here by Chantal Mouffe, who argues that “the political cannot be restricted to a certain type of institution, or envisaged as constituting a specific sphere or level of society. It must be conceived as a dimension that is inherent to every human society and that determines our very ontological condition.”<sup>26</sup> To say that something is “political” in this sense means that it is implicated in relations of power and that those relations, their assumptions, and their effects are contested and contestable, open to dissent and debate.

In other words, I’m concerned here with what Jodi Dean calls “the *how* of politics, the ways concepts and issues come to be political common sense and the processes through which locations and populations are rendered as in need of intervention, regulation, or quarantine.”<sup>27</sup> This focus on the *how* of politics parallels the first set of questions that motivate my project: Is disability political? How is it political? How is the category of disability used to justify the classification, supervision, segregation, and oppression of certain people, bodies, and practices? Addressing these questions

requires a recognition of the central role that ideas about disability and ability play in contemporary culture, particularly in imagined and projected futures.

After stressing the importance of the “how” of politics, Dean insists on the need “to take *depoliticization* seriously, to address the means through which spaces, issues, identities, and events are taken out of political circulation or are blocked from the agenda—or are presumed to have already been solved.”<sup>28</sup> Attending to the ways in which disability is political leads to my second set of motivating questions: How has disability been depoliticized, removed from the realm of the political? Which definitions of and assumptions about disability facilitate this removal? What are the effects of such depoliticization? I’m not so much arguing for or posing a chronology here—“disability used to be political and now it’s not”—as highlighting the need for disability studies to attend to the specific ways in which ableist understandings of disability are taken as common sense.<sup>29</sup> Such attention is vital in a context in which, as Susan Schweik notes, disability-based discrimination and prejudice are often condemned not as markers of structural inequality but of cruelty or insensitivity; this kind of rhetoric “sidesteps the reality of social injustice, reducing it to a question of compassion and charitable feelings.”<sup>30</sup>

These questions—of politicization and of depoliticization—lie at the root of my interest in political frameworks of the future: Do the futures I examine in these chapters assume and perpetuate the depoliticization of disability, and if so, how? What is it about disability that makes it a defining element of our imagined futures, such that a “good” future is one without disability, while a “bad” future is overrun by it? Why is disability in the present constantly deferred, such that disability often enters critical discourse only as the marker of what must be eliminated in our futures or what was unquestioningly eliminated in our pasts? And, most importantly, why are these characterizations taken for granted, recognized as neither partial nor political?

### Identifying Disability: Bodies, Identities, Politics

Seeing disability as political, and therefore contested and contestable, entails departing from the social model’s assumption that “disabled” and “nondisabled” are discrete, self-evident categories, choosing instead to explore the creation of such categories and the moments in which they fail to hold. Recognizing such moments of excess or failure is key to imagining disability, and disability futures, differently. Thus I understand the very meanings of “disability,” “impairment,” and “disabled” as contested terrain.<sup>31</sup> Disability can then be understood, in Jasbir Puar’s framework, as an *assemblage*, where “[c]ategories—race, gender, sexuality [and, I would add, disability]—are considered as events, actions, and encounters between bodies, rather than as simply entities and attributes of subjects.”<sup>32</sup>

Thus, a political/relational framework recognizes the difficulty in determining who is included in the term “disabled,” refusing any assumption that it refers to a discrete group of particular people with certain similar essential qualities. On the

contrary, the political/relational model of disability sees disability as a site of questions rather than firm definitions: Can it encompass all kinds of impairments—cognitive, psychiatric, sensory, and physical? Do people with chronic illnesses fit under the rubric of disability? Is someone who had cancer years ago but is now in remission disabled? What about people with some forms of multiple sclerosis (MS) who experience different temporary impairments—from vision loss to mobility difficulties—during each recurrence of the disease, but are without functional limitations once the MS moves back into remission? What about people with large birthmarks or other visible differences that have no bearing on their physical capabilities, but that often prompt discriminatory treatment?

Government and nongovernmental organizations alike frequently issue guidelines for determining who is disabled and thus eligible for certain programs and protections. Such groups, ranging from the World Health Organization to the US Social Security Administration, would not have to be so precise in defining “disability” if such definitions were without controversy; the very fact that so much energy is funneled into defining disability and impairment suggests the fundamental instability of the terms. Moreover, the desire for fixed definitions cannot be divorced from the economic effects of such fixing. The Social Security Administration uses its definitions of disability to determine who qualifies for benefits and at what level; the US Supreme Court has continued to revisit the Americans with Disabilities Act in order to determine who merits protection under its provisions and who does not. Both entities rule as if there were bright lines between disabled and non-, even though the need for such rulings suggests otherwise. But there is clearly a notion that there are people whose claims do not rise to the level of disability, and who therefore are undeserving of such protections.

In contrast, the disability theory and politics that I develop in these pages do not rely on a fixed definition of “disability” and “disabled person” but recognize the parameters of both terms as always open to debate. I am concerned here with disability not as a category inherent in certain minds and bodies but as what historian Joan W. Scott calls a “collective affinity.” Drawing on the cyborg theory of Donna Haraway, Scott describes collective affinities as “play[ing] on identifications that have been attributed to individuals by their societies, and that have served to exclude them or subordinate them.”<sup>33</sup> Collective affinities in terms of disability could encompass everyone from people with learning disabilities to those with chronic illness, from people with mobility impairments to those with HIV/AIDS, from people with sensory impairments to those with mental illness. People within each of these categories can all be discussed in terms of disability politics, not because of any essential similarities among them, but because all have been labeled as disabled or sick and have faced discrimination as a result. Simi Linton illustrates this fundamental diversity of the disability community when she writes,

We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on our breathing tubes, following our guide dogs, puffing and



sipping on the mouth sticks that propel our motorized chairs. We may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system. We are all bound together, not by this list of our collective symptoms but by the *social and political circumstances that have forged us as a group*.<sup>34</sup>

Linton's formulation strikes me as a fitting place to begin this exploration of accessible futures, primarily because it reads more as promise than fact. Both disability studies and disability movements have been slow to recognize potential linkages among people who hear voices, people with compromised immune systems, and people using wheelchairs. Although there have been notable exceptions, disability studies, especially in the humanities, has focused little attention on cognitive disabilities, focusing more often on visible physical impairments and sensory impairments.<sup>35</sup> Chronic illness has become more common in these discussions, but only in particular forms; discussion of chronic fatigue syndrome and mental disability has increased thanks to the work of scholars such as Susan Wendell, Ellen Samuels, and Margaret Price, but diabetes, asthma, and lupus remain largely unexplored by disability studies scholars.<sup>36</sup> (This oversight is all the more troubling given the fact that diabetes occurs disproportionately among "members of racial and ethnic minority groups in the United States," and asthma is a common side-effect of living in heavily polluted neighborhoods, which, unsurprisingly, are more likely to be populated by poor people.)<sup>37</sup> I repeat Linton's formulation then in an effort to call it into being, to invoke it as a possibility for thinking disability differently. I want to hold on to the possibility of a disability studies and a disability movement that does take all of these locations seriously, that feels accountable to these bodies and identities and locations.

One of the arguments I will make in this book, however, is that part of the work of imagining this kind of expansive disability movement is to simultaneously engage in a critical reading of these very identities, locations, and bodies. We must trace the ways in which we have been forged as a group, to use Linton's terminology, but also trace the ways in which those forgings have been incomplete, or contested, or refused. We need to recognize that these forgings have always already been infected by histories of race, gender, sexuality, class, and nation; failing to attend to such relations will ensure that disability studies remains, as Chris Bell puts it, "white disability studies."<sup>38</sup> We must, in other words, think through the assumptions and erasures of "disabled" and "disability," reckoning with the ways in which such words have been used and to what effect.

Doing so might mean imagining a "we" that includes folks who identify as or with disabled people but don't themselves "have" a disability. Scholars of chronic illness have started this work, arguing for the necessity of including within disability communities those who lack a "proper" (read: medically acceptable, doctor-provided, and insurer-approved) diagnosis for their symptoms. Doing so not only provides such people with the social supports they need (everything from access to social services to recognition from friends and family), it also presents disability less as diagnostic category

and more as collective affinity; moving away from a medical/individual model of disability means that disability identification can't be solely linked to diagnosis.

Less familiar, and potentially more complicated, would be people identifying with disability and lacking not only a diagnosis but any "symptoms" of impairment. How might we understand the forging of a group that includes, in Carrie Sandahl's and Robert McRuer's framings, a "nondisabled claim to be crip?"<sup>39</sup> Hearing Children of Deaf Adults, or CODAs, would be a clear example of this kind of identification, as CODAs consider themselves part of Deaf communities, and some even claim Deaf identity, but are not themselves deaf or hard-of-hearing.<sup>40</sup> But does claiming crip require this kind of blood or kinship tie? What might it mean for lovers or friends to claim crip, or to understand themselves as "culturally disabled"? Or for theorists and activists committed to rethinking disability and able-bodiedness/able-mindedness to make such claims? Can claiming crip be a method of imagining multiple futures, positioning "crip" as a desired and desirable location regardless of one's own embodiment or mental/psychological processes? As McRuer notes, these practices run the risk of appropriation, but they also offer a vital refusal of simplistic binaries like disabled/nondisabled and sick/healthy.<sup>41</sup> Claiming crip, then, can be a way of acknowledging that we all have bodies and minds with shifting abilities, and wrestling with the political meanings and histories of such shifts. Thus, to circle back to the notion of "we" as more promise than fact: thinking through what nondisabled claims to crip might entail will require exploring whether such claims might be more available, or more attainable, to some people than others (and on what basis).

Attention to these kinds of questions—the histories and effects of disability claims, the different availability and viability of disability identification—distinguishes this kind of "nondisabled claim to crip" from the well-intentioned but deeply ableist declaration that "we are *all* disabled." The latter obscures the specificities I call for here, conflating all experiences of physical, mental, or sensory limitation without regard to structural inequality or patterns of exclusion and discrimination. It is for this reason that Linton cautions against "erasing the line between disabled and nondisabled people," explaining that "naming the category" of disabled remains necessary because it effectively "call[s] attention to" disability-based discrimination. But I suggest that exploring the possibilities of nondisabled claims, as well as attending to the promises and dangers of the category's flexibility, can facilitate exactly this kind of critical attentiveness.<sup>42</sup> To claim crip critically is to recognize the ethical, epistemic, and political responsibilities behind such claims; deconstructing the binary between disabled and able-bodied/able-minded requires *more* attention to how different bodies/minds are treated differently, not less.

Attending to the epistemological challenges raised by disability claims introduces yet another set of questions about claiming crip. Thinking through this collective "we," this forging of crip communities, means accounting for those who do "have" illnesses or impairments, and who might be recognized by others as part of this "disabled we,"

but who do not recognize themselves as such. This group would include the largest proportion of disabled people: those folks with hearing impairments, or low vision, or “bum knees,” or asthma, or diabetes who, for a whole host of reasons, would claim neither crip identity nor disability. Even though most people with impairments might fall into this camp, it is actually the hardest group for me to address in this book; indeed, I think it is the hardest group for disability studies and disability rights activism to address.<sup>43</sup> Given my (our) focus on disability rights and justice, on radical queercrip activism, on finding disability desirable, how am I (how are we) to deal with those who want no part of such names?

One answer to these questions is that it doesn’t matter whether such people claim crip or not: rethinking our cultural assumptions about disability, imagining our disability futures differently, will benefit all of us, regardless of our identities. As Ladelle McWhorter notes, “The practices and institutions that divide, for example, the ‘abled,’ ‘sane,’ and ‘whole’ from the ‘impaired,’ ‘mentally ill,’ and ‘deficient’ create the conditions under which all of us live; they structure the situation within which each one of us comes to terms with ourselves and creates a way of life.”<sup>44</sup> As someone writing and teaching disability studies, as someone imagining readers and students with a whole range of bodies and minds, I find hope in McWhorter’s prediction, in her articulation of a better future. Much as feminist activism benefits people who want no part of feminism, disability studies and activism ideally benefit people who are not interested or invested in either.<sup>45</sup> At the same time, I’m certain this is not the only, or not the full, answer. As I embark on this journey into accessible futures, I want to highlight the question of crip affiliation, what it means, what it entails, what it excludes.

#### Feminist, Crip, Queer: A Note on Terms, Methods, and Affiliations

I became disabled before I began reading feminist theory, yet it was feminist theory that led me to disability studies. It was through reading feminist theoretical approaches to the body that I came intellectually to understand disability as a political category rather than as an individual pathology or personal tragedy. Feminist theory gave me the tools to think through disability and the ways in which assumptions about disability and disabled bodies lead to resource inequalities and social discrimination. Just as feminist theorists had questioned the naturalness of femininity, challenging essentialist assumptions about “the” female body, I could question the naturalness of disability, challenging essentialist assumptions about “the” disabled body. My understanding of the political/relational model of disability has been made possible by my engagement with the work of feminist theorists, an engagement that I hope will become clear in the following pages. Simply put, feminism has given me the theoretical tools to think critically about disability, the stigmatization of bodily variation, and various modes and strategies of resistance, dissent, and collective action.

I locate this project, then, within the larger field of feminist theory and politics. Although I examine a range of radical political visions, some explicitly feminist and

others less so, I understand my investment in radical politics as a feminist investment. As many historians of feminism and women’s studies have noted, feminism has long been interested in bridging theory with practice. Activists and scholars alike continue to explore the ways in which theory can inform political practice; conversely, feminists often theorize from practice, developing concepts and frameworks based on the strategies, conversations, conflicts, and achievements of feminist activists. My interest in radical politics derives in part from my theoretical and activist commitment to blending theory with practice, a commitment that I associate with feminism. I think it only appropriate to make this indebtedness explicit as I begin my exploration of possible futures, given recent disability studies texts that have downplayed or dismissed any connections to feminism; my readings and my imaginings are resolutely feminist.<sup>46</sup>

They also are undeniably crip, a term that has much currency in disability activism and culture but still might seem harsh to those outside those communities. Indeed, that harshness is a large part of its appeal, as suggested by essayist Nancy Mairs: “People—crippled or not—wince at the word ‘crippled’ as they do not at ‘handicapped’ or ‘disabled.’ Perhaps I want them to wince.”<sup>47</sup> This desire to make people wince suggests an urge to shake things up, to jolt people out of their everyday understandings of bodies and minds, of normalcy and deviance. It recognizes the common response of nondisabled people to disabled people, of the normative to the deviant—furtive yet relentless staring, aggressive questioning, and/or a turning away from difference, a refusal to see.<sup>48</sup> This wincing is familiar to many disabled people, but here Mairs turns it back on itself, almost wincing back. Like “queer,” “crip” and “cripple” are, in Eli Clare’s formulation, “words to help forge a politics.”<sup>49</sup>

Two related examples of such forging, of crafting an inducement to wince, would be Carrie Sandahl’s preference for “crip studies” and “crip theory” over “disability studies” and Robert McRuer’s decision to name his theoretical project *Crip Theory*. According to both Sandahl and McRuer, disability studies and crip theory differ in orientation and aim: crip theory is more contestatory than disability studies, more willing to explore the potential risks and exclusions of identity politics while simultaneously and “perhaps paradoxically” recognizing “the generative role identity has played in the disability rights movement.”<sup>50</sup> I see *Feminist, Queer, Crip* as engaging in exactly this kind of contradictory crip theory, and I use both “crip” and “crip theory” as a way to stake my claim alongside the activists and cultural workers engaged in these multiple sites of radical politics.<sup>51</sup>

One of the most productive and provocative elements of crip theory, and of crip in general, is the potential expansiveness of the term. As Sandahl notes, “cripple, like queer, is fluid and ever-changing, claimed by those whom it did not originally define. . . . The term crip has expanded to include not only those with physical impairments but those with sensory or mental impairments as well.”<sup>52</sup> I agree with Sandahl, and this potential flexibility is precisely what excites me about crip theory, but, as with Linton’s “we are everywhere,” this inclusiveness is often more hope than reality. Many expressions of



crip pride or crip politics often explicitly address only physical impairments, thereby ignoring or marginalizing the experiences of those with sensory or mental impairments. Others position crip as a way of naming opposition to cure, potentially making it difficult for “crip theory” to encompass the perspectives and practices of those who both claim disability identity and desire an end to their own impairments. Thus, I move back and forth between naming this project one of “feminist and queer disability studies” and one of “crip theory,” raising the possibility that the two can be, and often are, intertwined in practice; indeed, given the rich analyses of identity that circulate within feminist and queer studies, a “feminist and queer disability studies” may very well engage in the “paradoxical” approach to identity practiced in crip theory while making room for those who do not or cannot recognize themselves in crip.<sup>53</sup>

Similarly, throughout *Feminist, Queer, Crip*, I combine references to bodies with references to minds and pair “compulsory able-bodiedness” with “compulsory able-mindedness.”<sup>54</sup> If disability studies is going to take seriously the criticism that we have focused on physical disabilities to the exclusion of all else, then we need to start experimenting with different ways of talking about and conceptualizing our projects.<sup>55</sup> At the same time, I’m well aware that my use of such terms is partial in both senses of the word. I am invested in shifting the terrain of disability studies even as my own performances of it bear the marks of its current terrain, and I have only just begun to scratch the surface of what able-mindedness might mean in relation to able-bodiedness. Thus, as with Linton’s “we” and Sandahl’s “crip,” I use “mind” alongside “body” in the hope that writing and reading “bodies and minds” or “compulsory able-bodiedness/able-mindedness” makes me think disability differently. Rather than assuming that the mere use of such language is sufficient in and of itself, I’m calling for an engagement with the hard work of actually making such coalitions happen. As I suggest in the last chapter of the book, such expansiveness—mind and body, a crip of us all—can never be fully or finally achieved, but serves as a kind of hopeful horizon, “fluid and ever-changing,” as Sandahl notes, and used in ways unimagined in advance.

Queer (theory) readers will likely recognize this talk of fluidity, ever-changing horizons, and paradoxical treatments of identity as kin to queer projects, and, like Sandahl and McKrue, I position crip theory in general, and this project in particular, as such. “Queer” also remains contested terrain, with theorists and activists continuing to debate what (and whom) the term encompasses or excludes; it is this kind of contestation I welcome for disability. Indeed, Butler argues for queer as a “site of collective contestation” to be “always and only redeployed, twisted, queered.”<sup>56</sup> The circularity of that definition—queerness is something always to be queered—serves only to support this desire for dissent and debate. In naming my project “queer,” then, I am wanting both to twist “queer” into encompassing “crip” (and “crip,” “queer”) and to highlight the risks of such twisted inclusion. Critical examinations of compulsory able-bodiedness and compulsory able-mindedness are queer and crip projects, and they can potentially be enacted without necessarily flattening out or

stabilizing “crip” and “queer.”<sup>57</sup> What is needed, then, are critical attempts to trace the ways in which compulsory able-bodiedness/able-mindedness and compulsory heterosexuality intertwine in the service of normativity; to examine how terms such as “defective,” “deviant,” and “sick” have been used to justify discrimination against people whose bodies, minds, desires, and practices differ from the unmarked norm; to speculate how norms of gendered behavior—proper masculinity and femininity—are based on nondisabled bodies; and to map potential points of connection among, and departure between, queer (and) disability activists. As we shall see, one productive site for such explorations is the imagined future invoked in popular culture, academic theory, and political movements; *Feminist, Queer, Crip* begins to trace some of these queer/crip connections.

I want, then, to position this book as a fundamentally coalitional text. The “feminist, queer, crip” named in the title signals methodology as much as content. This work quite obviously, and necessarily, involves bringing disability identities and experiences to bear on existing feminist and queer theoretical frameworks. It is not simply, or not only, an additive intervention, however. While I am indeed arguing that disability needs to be recognized as a category of analysis alongside gender, race, class, and sexuality, my larger goal is to address how disability is figured in and through these other categories of difference.<sup>58</sup> What work does able-bodiedness do, for example, in feminist appropriations of the cyborg, or queer uses of reproductive technologies, or ecofeminist imaginings of a better life? How does reckoning with histories and experiences of disability, in other words, critique or transform feminist environmental philosophy or queer approaches to assisted reproductive technologies? I want to explore the theoretical terrain opened up by reading disability into those queer narratives and feminist analyses that never use the word “disability.” How might such readings shift our understandings of terms like “disabled,” or “queer,” or “feminist”? Or how might they expand our understanding of what it means to do cross-movement work, both in terms of theoretical development and activist practice? *Feminist, Queer, Crip* argues that a coalitional politics requires thinking disability, and disabled bodies, differently—recognizing the work done by disability and able-bodiedness/able-mindedness in different political visions, for example, or acknowledging the exclusions enacted in the desire for a unified disability community.

I know that in carefully delineating my affiliations here—feminist, queer, crip—I run the risk of further reifying these categories, thereby presenting them as discrete, separable identities. This kind of personal and theoretical positioning has long been a mainstay of feminist intersectional scholarship, and, as Puar warns, too easily requires the “stabilizing of identity across space and time.”<sup>59</sup> But taking such risks feels necessary because we are operating in a theoretical and activist context in which this combination of analytics and practices too rarely appears. It feels important at this particular moment to identify explicitly as feminist, queer, crip—even as I want to trouble such identifications—and to explicitly practice feminist, queer, crip work. I’m calling



attention to these shifting positions not to fix them in place, but to get them moving on the questions that face those of us committed to and invested in such positions.

I'm writing out of a concern, for example, about the silence of disability studies scholars and disability activists in response to how our movements have often (been) publicly aligned with the right. Where were the public feminist/queer/crip responses to Sarah Palin? How might we have intervened in the representation of her as a disability rights advocate, questioning the blurring of antichoice ideologies and disability critiques of prenatal testing? Or how might a feminist/queer/crip-informed analysis expand or complicate queer theoretical texts that rely on a trope of mobility for their analyses or that tend to allegorize rather than analyze disability and disabled bodies? Or, when only a small handful of papers and presentations at the annual Society for Disability Studies conference make explicit use of feminist and queer theories in their analyses, does it not become essential to name and inhabit these very intersections?<sup>90</sup> And, importantly, how can we do this kind of naming, demand these kinds of analytic and political practices, without stabilizing feminist/queer/crip or gender/sexuality/disability, without treating these very categories, nodes, and positions as themselves self-evident? I'm wanting this particular imagining of accessible futures—my imagining of accessible futures—to carve out a place on the theoretical/political map where feminist/queer/crip can feed and inform each other, even as they are already bound up in each other. More, I'm wanting this imagining to generate more such imaginings, such that the nodes on the map and the map itself multiply, proliferate, regenerate. We need multiple iterations of crip theory, ones that its practitioners might not always recognize, ones that contest and exceed its very parameters, and ones that take this particular iteration to task.

In the hopes of such proliferations, questions take center stage throughout *Feminist, Queer, Crip*. Part of this focus is stylistic, aesthetic; I like the cadence of a question. But it is also, and primarily, methodological. If one of my goals with this project is to get us to think disability differently, to begin to see both the category and the experience of disability as contested and contestable, then what better way to do that than to ask questions? (I've started already.) Rhetorical questions are common in conclusions as authors hint at their next projects, or discover new problems, or point toward the need for more research. I'm including such questions in the introduction as a reminder that I should imagine readers talking back, taking these ideas in new directions, turning my own questions back on me in different contexts or to different effects. The format of the question insists on seeing these complex subjects—the future of the child with Down syndrome or the desirability of disability—as debatable, contestable: as *in question*. It also opens up the possibilities of new answers, shifting answers, unforeseen answers. As I explain in the final chapter, I am interested in a crip politics of access and engagement that is resolutely a work in progress, open-ended, aiming for but never reaching the horizon. Questions keep me focused on the inconclusiveness of my conclusion, of the desire to think otherwise.

This book contains not only unanswered questions but also contradictions and logical inconsistencies. In chapter 3, for example, I am much more critical about desecting disability (i.e., terminating a pregnancy because tests reveal potential “genetic anomalies”) than I am about selecting for disability (i.e., using a sperm donor who carries a desired genetic trait), even though both practices involve parents wanting to have a child like themselves. Such contradictions are inevitable in a project like this one, reflecting our convoluted approaches to disability; I am writing in a culture in which inconsistency about disability is commonplace. Might it be logically inconsistent, for example, that we claim to value the lives of disabled people even as we create (and mandate) more and more prenatal tests to screen out “undesirable” fetuses? Glossing over these inconsistencies, or pretending that they can be easily and definitively resolved, simplifies the complexities inherent in questions of social justice. The desire for clear answers, free of contradiction and inconsistency, is understandable, but I want to suggest that accessible futures require such ambiguities. Following Puar, I believe that “contradictions and discrepancies . . . are not to be reconciled or synthesized but held together in tension. They are less a sign of wavering intellectual commitment than symptoms of the political impossibility to be *on one side or the other*.”<sup>91</sup> Indeed, part of the problem I'm tracing in these pages is the assumption that there is only one side to the question of disability and that we're all already on it.

In this spirit, my use of “we” and “they,” “them” and “us,” shifts throughout this book. To always use the third person in discussing disabled people would be to impose a distancing between myself and my subject that rings false. It also would run counter to this notion of “claiming crip,” denying the possibility of a deep and abiding connection to the identities, bodies, minds, and practices discussed here. At the same time, to always use the first person would be to answer in advance the question of a unified community of disabled people, to presume not only that we all share the same positions but also that one person—and in this case, I—can accurately represent the whole. In other words, when it comes to the vexed issue of personal pronouns, I will occasionally use “we/us” even when I am not an obvious member of the group being discussed, and, by the same token, will occasionally use “they/them” even when I am obviously included in the category. I do this to trouble the very notion of “obvious” identifications as well as the disabled/able-bodied and disabled/nondisabled binaries.<sup>92</sup> Even though I am a disabled person, I do not exist apart from the ableist discourses circulating through US society, to act as if my impairments render me immune to, or incapable of, ableist rhetoric and ideology would be to deny the insidiousness of compulsory able-bodiedness and able-mindedness.<sup>93</sup> “I,” Sedgwick reminds us, can be a powerful heuristic, and so can “we,” “they,” “you,” and “them.”<sup>94</sup>

## Overview of the Book

Whenever I tell people I have been working on a book about the role of disability in imagined futures, they almost always assume I'm writing about science fiction. I

understand their response: science fiction is full of “imagined futures,” and disabled characters are common in such novels (even if they aren’t referred to as “disabled” within the narratives themselves). I do indeed focus on stories in this book, but they are more the stories we tell ourselves as a culture—disability is a tragedy, children are our future—than the stories of literature or film.

Over the course of the book, I examine uses and representations of disability and able-bodiedness/able-mindedness across a range of sites in the contemporary United States. Given my future focus, and the ways in which the figure of the child often serves as a sign of the future, I pay particular attention to issues of reproduction, even as I work to unpack this elision between reproduction and futurity. Notions of space also play a key role here; disability rights activists have long worked to make more and more spaces accessible to disabled people, describing both flights of stairs and discriminatory hiring practices as barriers to access. As will become clear in the chapters that follow, spaces get imagined differently in different futures; creating accessible futures requires attention to space, both metaphorical and material.

Chapter 1, “Time for Disability Studies and a Future for Crips,” extends the theoretical frameworks established in this introduction, focusing primarily on the lenses of time and futurity. I begin to specify what I mean by “crip time,” positioning the project of *Feminist, Queer, Crip* alongside other work on queer temporality and critical futurity. Although rhetoric about futures—from warnings of slippery slopes to fears of deformity—permeates current discourses about disability, disability studies has yet to take up crip temporalities and futures as sites of extended analysis. In this chapter, then, I sketch out what is at stake in these frameworks, distinguishing “crip time” from “curative time” and working through what it means to project disability into the future.

The next two chapters focus on the question of medical intervention, addressing the ways in which the “future” is portrayed as a time of cures, genetic and otherwise. The cases under discussion here are characterized by a debate over the appropriate use of technology: technological attempts to eliminate disability are met with widespread praise and support because they are assumed to mark progress toward a better future, while refusals of such “healing” technology are condemned as backward and dystopic. Challenging the rhetoric of naturalness and inevitability that underlies these discussions, I argue that decisions about the future of disability and disabled people are *political* decisions and should be recognized and treated as such. 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. The first part of *Feminist, Queer, Crip* also zeroes in on the assumption that this kind of “elsewhere,” one without disability, is one “we” all want. Each of the chapters in this part of the book maps the ways in which disability is removed from debate, taken only as self-evident and given; these chapters unpack what it means to assume that we all want the same things.

In chapter 2, I analyze the case of Ashley X, a young disabled girl “frozen in time” through a growth attenuation regimen, hysterectomy, and bilateral mastectomy. These procedures, known as “the Ashley Treatment,” were seen as necessary by her parents and doctors to protect Ashley from future harms. According to this logic, Ashley’s body required intervention because her body was growing apart from her mind; physically, her body was developing rapidly, but mentally, her mind was failing to develop at all. As a result, she was embodied asynchrony; her mind and body were out of sync. By arresting the growth of Ashley’s body, the Treatment could stop this gap between mind and body from growing any wider. In order to make this argument, Ashley’s parents and doctors had to hold her future body—her *imagined* future body—against her, using it as a justification for the Treatment. Adding to the future framing of the case is the fact that both parents and doctors have offered the Treatment as a template for other children; they have expressed the hope that the Treatment will, in the future, become more widespread. The Ashley case, in other words, is shot through with temporal framings of the body/mind, especially the disabled body/mind, and with rhetoric about the future. As this case makes painfully clear, not all disability futures are desirable.

Using a popular example of feminist utopian fiction as an impetus for my continued exploration of cultural attitudes about disability, technology, and cure, chapter 3 begins with a description of Marge Piercy’s 1976 novel *Woman on the Edge of Time* and its evocation of a feminist utopia. While Piercy’s future is populated by peoples of all skin colors, genders, and sexualities, it is almost completely devoid of people with disabilities: advances in medicine have led to the elimination of most illnesses, and genetic “aberrations” have been eradicated or can easily be corrected. It is a utopia made possible by advances in reproductive technologies, and one frequently featured on women’s studies syllabi to discuss feminist futures. Inspired—and troubled—by Piercy’s novel, I speculate on the place of disability in the future, questioning whether “utopia,” by definition, excludes disability and illness. I focus on the use of reproductive technologies to screen out disability, highlighting the ways in which the expansion of such tests presumes the desire for futures without disability. In this context, parents who refuse such tests or, especially, who use them to select *for* disability, are portrayed as leading the nation down a slippery slope. The 2002 story of Sharon Duchesneau and Candace McCullough, a Deaf lesbian couple who used a deaf sperm donor to conceive their children, anchors my reflection on what it might mean to choose futures of disability.

Chapter 4 maintains a focus on reproduction, but looks more broadly at the reproduction of “community values” and the place of disability in such constructions. In this chapter, I offer a close reading of a widespread public service campaign in the United States, one that has reached billboards, bus shelters, movie theaters, and television stations all over the country. In the years since 9/11, the philanthropic organization Foundation for a Better Life (FBL) has funded a campaign touting “community values”



and “character development,” arguing that these values will result in a “better life” and future for the United States. Positioning itself as nonpartisan, the FBI’s mission is to foster individual and collective betterment through values education and engagement. It is this positioning that I want to examine here: this attempt to depoliticize notions of community, this assumption of shared values, and this articulation of what a better life entails. By presenting these concepts as apolitical, the FBI renders them natural, accepted, common sense, and therefore beyond the scope of debate or discussion. Representations of disability and illness play a large role in this campaign, with a majority of billboards praising individuals with disabilities for having the strength of character to “overcome” their disabilities. The depoliticization mandated by these billboards and the FBI itself is made possible through reference to the disabled body. Indeed, the presence of the disabled body is used to render this campaign not as ideology but as common sense. The billboards seem to promise a future that includes disability—disabled people are a highly visible presence in the campaign—but disability appears here only as the site for personal triumph and overcoming.

In the next section of the book, I turn to two existing frameworks for thinking disability futures: cyborg theory and environmentalism. Both of these bodies of theory have explicitly imagined what a better future might look like, and, in doing so, have relied on tropes of disability, illness, and hyper-ability in their constructions. After making this figuration of ability/disability apparent, I explore the ways in which these same bodies of knowledge can be reimagined from feminist, queer, and crip perspectives.

Chapter 5 examines the figure of the cyborg, focusing on its appearance in feminist theories of politics, a use that began with Donna Haraway and continues in the work of theorists such as Malini Johar Schueller, Anne Balsamo, and Jennifer Gonzalez. In her “cyborg manifesto,” Haraway positions the cyborg figure as an intervention in feminist theory and politics, using it to critique the reductionist approaches to technology and the exclusionary definitions of “women” that pervaded feminist thought in the 1970s and 1980s. She argues that the cyborg can offer a model for how to do feminist politics, suggesting that the figure can be useful in imagining a feminist “elsewhere.” But what is the place of disability in her imagining? Can the cyborg figure offer an effective model for a feminist disability theory and politics? Does it facilitate the articulation and creation of an anti-ableist “elsewhere”? As I argue, cyborg theories, because of their focus on cybertechnologies and human/machine interfaces, tend to represent disability exclusively as an individual, medical problem, a positioning that depoliticizes disability and disabled people. This contemporary understanding of disability, evident in the frequent use of disabled bodies as illustrations of cyborgism, presents a future vision of technological and medical intervention—not social transformation or political action—as the only proper response to disability. However, the practices and identifications of queer disability activists begin to hint at ways of crippling this cyborg legacy.

In a 1991 interview in the *Socialist Review*, Donna Haraway notes that her articulation of the cyborg stems from a commitment to ecofeminism, and theorists from Stacy Alaimo to Catriona Sandilands take Haraway at her word, incorporating the figure into their own ecofeminist theorizing. Following this cyborgian trail, I turn in chapter 6 to the role disability and able-bodiedness play in representations of nature and environmentalism. Ecofeminist visions of the future cannot be reduced to one coherent story; there are many different ecofeminist futures and perhaps even more different ways of imagining ecofeminist politics. Many of these visions, however, are rooted in contemporary ableist assumptions about how bodies look, move, sense, communicate, and think. Environmental conceptualizations of nature tend to assume that everyone accesses nature in the same way, and it is this presumption that colors environmental political visions. Nonnormative approaches to nature and the limitations of the body are erased; able-bodiedness becomes a prerequisite for imagining environmental futures. If disabled people are believed to lack the physical and mental capacities to access and experience nature in the present, then they can play no role in environmental understandings of nature in the future. Drawing on the work of crip artists and writers, I argue that the embodied experience of illness and disability presents alternative ways of understanding ourselves in relation to the environment, understandings which can then expand ecofeminist frameworks and current practices in environmental activism.

Each of these future visions—cyborg theory, environmentalism, and genetic utopianism—is characterized by a normalizing impulse, an impulse that is made apparent when viewed through the lens of disability. Adhering to ideologies of wholeness, cyborg theory attempts to normalize the disabled body through prosthetics and technological intervention, striving to make disabled bodies (appear) whole. Environmentalists often predicate their theories on the experiences of the nondisabled body, normalizing the body itself by marginalizing its limitations, buttressing ideals of hyper-ability and able-bodiedness, and erasing the experiences and insights of disabled people. Finally, genetic discourses frequently advocate genetic testing and selective abortion, normalizing the body/mind by testing disability out of existence.

It is possible, however, to theorize an “elsewhere,” to provide a political framework for a more just world that does not rely on a normalizing impulse. Queer theorists are committed to forging a politics that does not marginalize, normalize, or criminalize queer bodies, practices, or desires; feminist theorists are engaged in imagining open-ended politics that do not attempt to normalize all women under a unified category of “woman.” Building on these frameworks, disability theorists are actively imagining anti-ableist futures, theorizing what Robert McRuer and Abby Wilkerson call “desirably disabled” worlds that are not founded on the normalization of disabled people.<sup>65</sup> I position my text as part of this queer/feminist/disability project of imagining desirably queer/feminist/disabled worlds. By exposing the ableist assumptions embedded in future visions of genetic and biomedical intervention while simultaneously suggesting

ways in which these ableist ideologies can be subverted, I reject the widespread depoliticization of disability.

It is this refusal that fuels, at least in part, my attempt to offer anti-ableist political visions of “elsewhere.” Chapter 7, “Accessible Futures, Future Coalitions,” represents my attempt to counter this erasure of disability from the political, this tendency to marginalize disabled people in political visions of the future. Building on the insights of feminist and queer theorists, queer disability activists, and disability studies scholars, I sketch the parameters of yet another idea of how to get “elsewhere,” but one that welcomes, relishes, and desires disability, one that recognizes disability as political. This crip vision of elsewhere remains, by definition and by design, incomplete. In this final chapter, I explore three potential sites for coalition politics—trans and gender-queer bathroom access, environmental justice, and reproductive rights and justice—in order to develop a crip futurity that finds value in dissent and disagreement, that recognizes loss, that remains open. Using these three sites of possibility, I speculate on how we might extend and challenge the parameters of disability theory and politics, a theory and politics which too rarely engages in serious coalition work with other movements, communities, and inquiries. Reading narratives and movements as crip, even when they do not explicitly mention disability, might lead all of us to begin thinking disability, and disability futures, otherwise.

# 1 Time for Disability Studies and a Future for Crips

Queerness should and could be about a desire for another way of being in both the world and time, a desire that resists mandates to accept that which is not enough.

—José Esteban Muñoz, *Cruising Utopia*

WHAT WOULD IT mean to explore disability in time or to articulate “crip time”? Temporal categories are already commonly used in formulations of disability; one aspect of crippling time might simply be to map the extent to which we conceptualize disability in temporal terms. The medical field in particular has a long tradition of describing disability in reference to time. “Chronic” fatigue, “intermittent” symptoms, and “constant” pain are each ways of defining illness and disability in and through time; they describe disability in terms of duration. “Frequency,” “incidence,” “occurrence,” “relapse,” “remission”: these, too, are the time frames of symptoms, illness, and disease. “Prognosis” and “diagnosis” project futures of illness, disability, and recovery. Or take terms such as “acquired,” “congenital,” and “developmental,” each of which is used to demarcate the time or onset of impairment. “Developmental” does double duty, referring both to lifelong conditions, including those that develop or manifest in childhood and adolescence, but also implying a “delay” in development, a detour from the timeline of normative progress.<sup>1</sup>

Temporal frameworks are not limited to the medical field, however. Disability studies and disability movements also draw on discourses of temporality in their framings of disability, often using the same temporal terms mentioned above. Indeed, part of the work of these movements has been to reveal “nondisabled” and “able-bodied” as temporal, and temporary, categories; think here of the “TAB” tag (temporarily able-bodied), intended to remind nondisabled people that the abled/disabled distinction is neither permanent nor impermeable.<sup>2</sup> Disability studies’ well-rehearsed

mantra—whether by illness, age, or accident, all of us will live with disability at some point in our lives—encapsulates this notion, suggesting that becoming disabled is “only a matter of time.” Sharon Snyder, Brenda Bruggemann, and Rosemarie Garland-Thomson call this temporality of inevitability “the fundamental aspect of human embodiment.”<sup>3</sup> Of course, disability is more fundamental, more inevitable, for some than others: the work that one does and the places one lives have a huge impact on whether one becomes disabled sooner or later, as do one’s race and class positions.<sup>4</sup> Yet these patterns can also be understood in terms of temporality: *frequency*, *incidence*, *occurrence*. Familiar categories of illness and disability—congenital and acquired, diagnosis and prognosis, remission and relapse, temporarily able-bodied and “illness, age, or accident”—are temporal; they are orientations in and to time, even though we rarely recognize or discuss them as such, and could be collected under the rubric of “crip time.”

Exploring disability in time also includes speculation on temporalities of disability: how might disability affect one’s orientation to time? Irv Zola and Carol Gill were perhaps the first disability studies scholars to mention the temporal orientation of “crip time,” describing it as an essential component of disability culture and community. Tellingly, neither one of them defined the term but rather focused on its frequent appearance in disability communities: they wrote as if the concept would be already familiar to their readers. For Zola, discussing “the intricacies of crip time” was an important act of political reclamation for disabled people; Gill reports feeling pleasure and surprise at discovering “the common usage and understanding” of crip time among the diverse groups of disabled people she encountered.<sup>5</sup> By locating crip time in disabled people’s in-group conversations, Gill and Zola center community-based temporalities, ones which they equate with disability culture and resistance.

Crip time emerges here as a wry reference to the disability-related events that always seem to start late or to the disabled people who never seem to arrive anywhere on time.<sup>6</sup> As one slang dictionary puts it, “crip time” means both “a flexible standard for punctuality” and “the extra time needed to arrive or accomplish something.”<sup>7</sup> This need for “extra” time might result from a slower gait, a dependency on attendants (who might themselves be running late), malfunctioning equipment (from wheelchairs to hearing aids), a bus driver who refuses to stop for a disabled passenger, or an ableist encounter with a stranger that throws one off schedule. Operating on crip time, then, might be not only about a slower speed of movement but also about ableist barriers over which one has little to no control; in either case, crip time involves an awareness that disabled people might need more time to accomplish something or to arrive somewhere.<sup>8</sup>

Recognizing some people’s need for “more” time is probably the manifestation of crip time most familiar to those of us in the academy. Disabled students (or at least those with approved paperwork) are permitted more time on exams, for example, or granted extended reading periods. But “crip time” means more than this kind of

blanket extension; it is, rather, a reorientation to time. As Margaret Price explains, “[A]dhering to crip time . . . might mean recognizing that people will arrive at various intervals, and designing [events] accordingly; and it might also mean recognizing that [people] are processing language at various rates and adjusting the pace of a conversation. It is this notion of *flexibility* (not just ‘extra’ time) that matters.” Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of “how long things take” are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need “more” time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.

How might thinking about time open new perspectives on and for disability studies? Or how might observations on “crip time” lead to more expansive notions of both time and futurity? Questions about time, temporality, and futurity continue to animate queer theory, but this work has yet to have much of an impact in disability studies, and disability studies scholars have rarely been participants in these discussions.<sup>10</sup> In articulating crip temporalities, then, I am calling for a mutual engagement in these discourses: What can disability studies take from queer work on critical futurity and, simultaneously, how might attention to disability expand existing approaches to queer temporality? How might our understandings of queer futurity shift when read through the experiences of disabled people, or when interpreted as part of a critique of compulsory able-bodiedness or able-mindedness? What does it do to queer time to place it alongside crip time, or queer futurity alongside crip futurity? Can we crip queer time?

In offering these questions, my call is not only for disability studies to enter into theoretical discussions about time, temporality, and futurity, but also for us to wrestle with the ways in which “the future” has been deployed in the service of compulsory able-bodiedness and able-mindedness. Ideas about disability and disabled minds/bodies animate many of our collective evocations of the future; in these imaginings, disability too often serves as the agreed-upon limit of our projected futures. This book is about imagining futures and futurity otherwise.

My understanding of crip time and my desire for crip futurity exist in stark contrast to the temporal framing more commonly applied to disability and disabled people, what I call “curative time.” I use “curative” rather than “cure” to make clear that I am concerned here with compulsory able-bodiedness/able-mindedness, not with individual sick and disabled people’s relationships to particular medical interventions; a desire for a cure is not necessarily an anti-crip or anti-disability rights and justice position. I am speaking here about a *curative imaginary*, an understanding of disability that not only *expects* and *assumes* intervention but also cannot imagine or comprehend anything other than intervention.



Futurity has often been framed in curative terms, a time frame that casts disabled people (as) out of time, or as obstacles to the arc of progress. In our disabled state, we are not part of the dominant narratives of progress, but once rehabilitated, normalized, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body.<sup>12</sup> Within this frame of curative time, then, the only appropriate disabled mind/body is one cured or moving toward cure. Cure, in this context, most obviously signals the elimination of impairment but can also mean normalizing treatments that work to assimilate the disabled mind/body as much as possible. The questions animating a curative temporality include: Were you born that way? How much longer do you have to live this way? How long before they invent a cure? How long will a cure take? How soon before you recover?<sup>13</sup>

In this chapter, I engage in the process of articulating other temporalities, other approaches to futurity beyond curative ones. I do so by speculating on the possibilities of crippling queer time. First, I briefly summarize Lee Edelman's infamous queer polemic against the future. Although my larger project is concerned with how notions of the future have been used against disabled people, I argue that abandoning futurity altogether is not a viable option for crip or crip theory. Second, I read queer temporality through the lens of disability, exploring how illness, disability, and crip time are always already present in queer time. Third, I continue this reading of queer time through disability to pinpoint places where disability seems to exceed queer time. My interest is in how we might use these points of disconnection to expand both queer and crip time. Finally, I close with a few reflections on thinking disability in time. As critics of utopian thinking have long argued, the futures we imagine reveal the biases of the present; it seems entirely possible that imagining different futures and temporalities might help us see, and do, the present differently.

### No Future for Crips

Lee Edelman has famously argued that queers and queer theory would be better off refusing the future altogether. ("Fuck the Future," as Carla Freccero puts it.)<sup>14</sup> Building on Lauren Berlant's work on the figure of the child in American politics, Edelman argues that futurity—an investment in and attention to the future or futures—is almost always figured in reproductive terms: we cannot "conceive of a future without the figure of the Child."<sup>15</sup> As a result, the Child serves as "the telos of the social order," the one for whom we all act, "the fantasmatic beneficiary of every political intervention."<sup>16</sup> He offers as an example abortion rhetoric, noting that both pro-choice and antiabortion activists frame their fight as on behalf of the children.<sup>17</sup> Patrick McCreery traces a similar parallel among both opponents and supporters of gay marriage: depending on one's stance, gay marriage either destroys children's well-being or enhances it, but both sides agree that the future of children is what is at stake in the debate and therefore what should guide our decisions.<sup>18</sup> For those in both fights, then, the struggle becomes no longer about rights or justice or desire or autonomy but about the future of "our" children. Both of these

examples show the slipperiness of arguments based on the Child and reproductive futurity; one can mobilize the same rhetoric toward mutually opposing goals. What Edelman draws out is the coercive nature of such frames: it is not only that we *can* use the "future of our children" frame but that we *should* or *must* use it; politics itself is and can only be centered around the Child, foreclosing all other possibilities for action.

Reading from a queer crip perspective, I can easily see the ways in which "the future," especially as figured through the "Child," is used to buttress able-bodied/able-minded heteronormativity. First, the proliferation of prenatal testing, much of which presumes that all positive diagnoses will be "solved" through selective abortion, is a clear manifestation of compulsory able-bodiedness and able-mindedness. As we will see in the following chapters, pregnant women with disabilities and pregnant women whose fetuses have tested "positive" for various conditions are understood as threats to the future: they have failed to guarantee a better future by bringing the right kind of Child into the present.<sup>19</sup> Thus the idealization of the Child as the frontier of politics, the framing that troubles Edelman, should concern crip readers as well; discourses of reproduction, generation, and inheritance are shot through with anxiety about disability. These sites of reproductive futurity demand a Child that both resembles the parents and exceeds them; "we" all want "our" children to be more healthy, more active, stronger and smarter than we are, and we are supposed to do everything in our power to make that happen. The Child through whom legacies are passed down is, without doubt, able-bodied/able-minded.

Second, a politics based in futurity leads easily to an ethics of endless deferral. "We're held in thrall by a future continually deferred by time itself," Edelman notes, and this deferment serves to consolidate the status quo.<sup>20</sup> Focusing always on the better future, we divert our attention from the here and now; "We are rendered docile," in other words, "through our unwitting obedience to the future."<sup>21</sup> This phrasing is telling: "held in thrall," "rendered docile," "unwitting obedience"—each phrase signals stagnation and acquiescence, an inability to move in any direction because of a permanently forward-looking gaze. This deferral, this firm focus on the future, is often expressed in terms of cure and rehabilitation, and is thereby bound up in normalizing approaches to the mind/body. Disability activists have long rallied against a politics of endless deferral that pours economic and cultural resources into "curing" future disabled people (by preventing them from ever coming into existence) while ignoring the needs and experiences of disabled people in the present.<sup>22</sup> This kind of focus on futurity does disabled people no favors, yet it is one of the most common ways of framing disability: we must cure Jerry's kids now so that there will be no more Jerry's kids in the future. Moreover, everything from sterilization to institutionalization, from bone-lengthening surgeries to growth attenuation, has been justified on the grounds that such acts will lead to better futures for the disabled person and/or for their communities. Within these discourses, disability cannot appear as anything other than failure.

Third, eugenic histories certainly bear the mark of reproductive futurity. Even keeping only to the United States, and only to the past one hundred years or so, examples abound of how concerns about the future of the “race” and the future of the nation (futures often depicted as intertwined) have been wrapped up in fears and anxieties about disability. Tens of thousands of people diagnosed with various “defects” were targeted by eugenic professionals and policies for the first half of the twentieth century, classified, and managed in order to contain the alleged risks they posed to public health. The category of “defectives” included not only people with disabilities but also people from “suspect” racial, ethnic, and religious groups as well as poor people, sexual “delinquents,” and immigrants from the “wrong” countries. All were united under flexible concepts of degeneracy, defect, and disability, with “feeble-minded” serving as one of the most effective, and expansive, classifications of all. People placed into one or more of these categories might be tracked by family records offices, institutionalized and segregated from the public, sterilized against their will, barred from entering the country, or, in extreme cases, euthanized. Schools and universities included the study of eugenics in their curriculum, both disseminating and relying on these concepts of degeneration and defect. In many states, sterilization came to be seen as a necessary means of protecting the health of the race and the nation from further degeneration; as Oliver Wendell Holmes asserted in the infamous 1927 *Buck v. Bell* decision upholding Virginia’s compulsory sterilization policies, “Three generations of imbeciles are enough.”<sup>23</sup> While many overtly eugenic policies began to wane in the 1930s and 1940s, eugenic ideologies and practices did not fully disappear but rather flourished well into the Cold War and beyond.<sup>24</sup>

Virginia’s sterilization law was not repealed until 1974, and coerced or forced sterilization of women of color, poor women, indigenous women, and disabled women persisted throughout most of the twentieth century; even today, under certain circumstances, disabled people can be sterilized without their consent, and poor women, immigrant women, and women of color continue to have their reproductive futures curtailed by the courts and the legislature.<sup>25</sup> Institutionalization remains a common response to disabled people, particularly those with “severe” disabilities; despite the Supreme Court’s 1999 decision in *Olmstead*, which affirmed the right of disabled people to live in their home communities, many states continue to prioritize funding for institutions over funding community-based care.<sup>26</sup> State governments across the country are responding to budget crises with cuts to health care and disability services, especially in-home attendant care; given that many disabled people require such services in order to live independently, disability rights activists and health advocates note that even more disabled people, especially disabled people of color and low-income disabled people, are being forced into nursing homes or out onto the street. These trends do not bode well for the futures of disabled people, even as they are touted as necessary for preserving the future health of the state and the nation.

Indeed, at one time or another, each of these practices—sterilization, segregation, exclusion, institutionalization—has been justified by concerns about “the future” and particularly future children. For example, Mary Storer Kostir, an assistant at the Ohio Bureau of Juvenile Research, argued in a 1916 publication that “*physically rigorous but mentally feeble persons are a social menace . . . Their children threaten to overwhelm the civilization of the future. . . . [We] must also consider our children, and not burden the future with an incubus of mental deficiency.*”<sup>27</sup> In making her case for segregating those labeled “feeble-minded,” Kostir weighs the futures of “our” children against those other children, the ones who are mentally deficient, threatening, and burdensome. A 1933 pamphlet by the Human Betterment Foundation similarly warns against the “burden” of “feeble-minded” children, noting that the failure to practice “eugenic sterilization” produces effects that are “disastrous . . . in future generations.”<sup>28</sup> In these kinds of eugenic discourses, children serve as the sign of the future: the kind of future that awaits us will be determined by the kind of children we bear. Illness, “defect,” “deviance,” and disability are positioned as fundamentally damaging to the fabric of the community: polluting the gene pool, or weakening the nation, or destroying a family’s quality of life, or draining public services (or, often, some combination of the four). To put it bluntly, disabled people were—and often are—figured as threats to futurity.

Whole books have been written about each of these practices, and this brief, sweeping history cannot begin to do justice to the material or, especially, to the bodies invoked by this material. Such broad summaries all too easily erase differences among people with disabilities; differences not only of race, class, sexuality, gender, and history but also of impairment; there are many bodies falling through the cracks of this overview. And yet, it is imperative to establish a pattern, to demonstrate that we have long felt and acted on the belief that disability destroys the future, or that a future with disability must be avoided at all costs. It is this pattern, these histories, that makes the question of the future so vexed. I can see clearly how futurity has been the cause of much violence against disabled people, such that “fuck the future” can seem the only viable crip response.

And yet, these very histories ultimately make such a refusal untenable, and it is here that I part ways with Edelman. I do not think the only response to no future—or, rather, to futures that depend upon no futures for crips—is a refusal of the future altogether. Indeed, “fucking the future,” at least in Edelman’s terms, takes on a different valence for those who are *not* supported in their desires to project themselves (and their children) into the future in the first place.<sup>29</sup> Edelman acknowledges that “the image of the Child [is] not to be confused with the lived experiences of any historical children,” and his imperative to reject the future is therefore not so much about the futures of actual children as about “the whole network of Symbolic relations and the future that serves as its prop.”<sup>30</sup> I am, then, writing in a different register, and somewhat simplifying Edelman’s argument in the process. Yet, at the same time, Edelman’s warnings of reproductive futurism, of idealizing the child, read quite differently when



they are read alongside “the lived experiences of . . . historical children.” As Heather Love urges, “What one wants more of . . . are things that *No Future* excludes from the start: an account of the relation between the idealization of children and their actual treatment in the world.”<sup>31</sup> José Esteban Muñoz offers the kind of accounting we need here, noting that the futures of some children are neither protected nor fetishized: “Racialized kids, queer kids, are not the sovereign princes of futurity. Although Edelman does indicate that the future of the child as futurity is different from the future of actual children, his framing nonetheless accepts and reproduces this monolithic figure of the child that is indeed always already white.”<sup>32</sup>

This always already whiteness is a whiteness framed by and understood through regimes of health and hygiene; health and hygiene have long served as “potent symbolic marker[s] of racial difference” in terms of both immigration policies and conceptualizations of disability and illness.<sup>33</sup> Anna Stubblefield details, for example, the ways in which the label of “feeble-mindedness” worked in the early twentieth century to signify a whiteness “tainted” by poverty and ethnicity; “[T]he racialized understanding of cognitive ability was used to signify not only the difference between white and nonwhite people but also the difference between pure and tainted whites.” Whiteness, in other words, depended on the linkage of race, class, and disability for meaning.<sup>34</sup> Citizenship has been similarly policed; Sarah Horton and Judith C. Barker offer the example of oral health campaigns targeted toward Mexican immigrant families in the early 2000s, with the children’s poor dental health cast as evidence of the parents’ “unfitness” for inclusion in the body politic.<sup>35</sup>

Queer kids, kids of color, street kids—all of the kids cast out of reproductive futurism—have been and continue to be framed as sick, as pathological, as contagious. The histories of eugenic segregation and sterilization I mention above offer multiple examples of this conflation of race, class, and disability; so, too, does Daniel Patrick Moynihan’s infamous 1965 report *The Negro Family: The Case for National Action*. In it, he warns that “most Negro youth are in danger of being caught up in the tangle of pathology that affects their world, and probably a majority are so entrapped.” They are “entrapped,” explains Moynihan, because this “pathology” is endemic to black families; the black family is always already sick.<sup>36</sup> We can locate a more recent example of the linkages among race, class, and illness in the 2009 finding that doctors are four times more likely to prescribe antipsychotic drugs to children on Medicaid than children on private insurance; children on Medicaid are also far more likely to be prescribed such medications for “less severe conditions” than other children. As Dorothy Roberts notes, such differential treatment suggests the persistence of stereotypes about the mental health and behavioral stability of poor children and children of color.<sup>37</sup> I offer these examples not to make the case that racism and classism are really ableism, or that what Muñoz is *really* talking about is disability, as if everything collapses into disability; rather, I want to insist that these categories are constituted through and by each other. The always already white Child is also always already healthy and

nondisabled; disabled children are not part of this privileged imaginary except as the abject other.

In highlighting this abjection, I am not simply arguing for an expansion of the privileged imaginary to include disabled children; as Robert McRuer makes clear, the crip call is not to become normative.<sup>38</sup> On the contrary, I want to interrupt this privileged imaginary by making apparent its assumptions; echoing Love’s desire for a careful accounting of real children’s lives, I call for critical maps of the practices and ideologies that effectively cast disabled people out of time and out of our futures. Let us return, then, to some of the terms with which I began this exploration of crip futures and temporalities: “frequency,” “incidence,” “occurrence.” Jasbir Puar argues that the task at hand is not to repudiate reproductive futurities but to trace “how the biopolitics of regenerative capacity already demarcate racialized and sexualized statistical population aggregates as those in decay, destined for no future, based not on whether they can or cannot reproduce children but on what capacities they can and cannot regenerate.”<sup>39</sup> She speaks, then, not only of disability futurity but of futures of disability: how are incidents of illness and disability inextricably bound, and differentially bound, to race/class/gender/nation?

Noam Ostrander’s interviews with young black men in Chicago, each with violently acquired spinal cord injuries, are a useful illustration of these concerns. Several of these men describe being treated as if their current disablement were a foregone conclusion; people act as if they had always expected to find disability in these men’s futures because of their gender, race, and class: of course you’re in a wheelchair, what other futures could you possibly expect? As Isaac explains, “[B]ecause I’m black, I’m supposed to get in trouble—stuff like this is supposed to happen . . . I’m supposed to be dead in jail or in a chair. Some people look at it like that and that kinda bothers me. Just because I’m an African-American that means what? . . . This is how our lives is?”<sup>40</sup> The statistical likelihood that young, black men living in particular Chicago neighborhoods will be paralyzed (if not killed) by gunshot wounds serves to push them out of time, facing a future of no future, and a no future best embodied by a wheelchair. Disability, in other words, becomes the future of no future, with “dead in jail or in a chair” recognized as all the same, all signs of no future. In more mainstream, sentimental accounts of disability (i.e., those not featuring poor people of color living in “bad” neighborhoods), disability is what ends one’s future; it is the familiar narrative of disability as tragedy and loss. But for the men Ostrander profiles, disability is the sign that one never had a future in the first place; loss is not the defining frame because there was nothing to “lose.”

This assumption is laid bare in the results of a 2008 study of Medicare claims that describes the impact of race and region on health care. Researchers found, for example, that “blacks with diabetes or vascular disease are nearly five times more likely than whites to have a leg amputated”; an earlier study found similar racial disparities in medical responses to prostate cancer, with black men more likely than whites to have

their testicles removed as part of treatment.<sup>41</sup> These differences are due in no small part to the larger disparities in our health care system; black people likely face more drastic treatments because their diagnoses come later and/or because they lack regular access to the high-quality care needed to manage chronic illnesses successfully. But whether we look at the end result—higher rates of amputation and thus of disability—or at the process—unequal access to care—it is hard to deny that some futures (and some bodies) are more protected than others.

The task, then, is not so much to refuse the future as to imagine disability and disability futures otherwise, as part of other, alternate temporalities that do not cast disabled people out of time, as the sign of the future of no future. It is to do the work Love, Muñoz, and Puar call for, and to do it with attention to how different populations are demarcated differently. The questions that then hang around us, that require sustained attention from queer disability scholars, would be the very ones raised by these queer theorists: How does the Child differ from historical children? How do some kids become the “sovereign princes of futurity” while others don’t (or perhaps *because* others don’t)?<sup>42</sup> Pursuing these kinds of questions makes clear that some populations are already marked as having no future, as destined for decay, as always already disabled.

### Queer Time, Crip Time

One could argue that queer time is crip time, and that it has been all along. Queer time is often defined through or in reference to illness and disability, suggesting that it is illness and disability that render time “queer.” Not only might they cause time to slow, or to be experienced in quick bursts, they can lead to feelings of asynchrony or temporal dissonance; depression and mania are often experienced through time shifts, and people with various impairments move or think at a slower (or faster) pace than culturally expected. These shifts in timing and pacing can of necessity and by design lead to departures from “straight” time, whether straight time means a firm delineation between past/present/future or an expectation of a linear development from dependent childhood to independent reproductive adulthood. Glimpses of these possibilities can be seen in recent queer theory. Elizabeth Freeman, for example, begins the “Queer Temporalities” issue of *GLQ* with a hint that illness and disability might be catalysts to thinking time differently, or *queerly*, riffing on Shakespeare’s “the time is out of joint,” she links this description of “skeletal dislocation” to a queer asynchrony, an experience of time in, on, and across the body. Imagining time as “out of joint” allows the possibility that time’s “heterogeneity can be felt in the bones,” that time “is” a body.<sup>43</sup> Just as quickly as she names this dislocation or disability, however, she moves away from it, focusing only on queer temporalities “beyond somatic changes like puberty, aging, or illness.”<sup>44</sup> What happens, though, if we do not move “beyond somatic changes” but think about queer/crip temporalities *through* such changes, through these kinds of skeletal dislocations, or illness, or disease?

In an attempt to begin that kind of inquiry, I use this section to trace potential links and overlaps between queer temporalities and what we can call “crip time.” I

focus primarily but not exclusively on Judith Halberstam, not only because she has written extensively on the possibilities of queer temporalities but also because her work so clearly approaches the terrain of disability studies (even though she has yet to mark that closeness).<sup>45</sup> If queerness is, in Freeman’s terms, “a set of possibilities produced out of temporal and historical difference,” and thus a kind of temporality (or temporalities), then thinking through queer disability requires thinking about crip temporalities.<sup>46</sup> I am particularly interested in highlighting the work of illness and disability in articulations of queer time, drawing out the ways in which queer theorists deploy ideas of illness or disability to define queer time. Although I argue that disability categories are already at work in queer temporalities, I think there is more to be done in terms of tracing or creating connections, and I begin some of that work here, using queer temporalities to read disability experiences and reading crip temporalities as resembling queer time.

For Halberstam, queers are queer not only because of their objects of desire but also because they do too much of the wrong thing at the wrong time; attending to queer temporalities enables us to see queerness as “more about a way of life than a way of having sex.”<sup>47</sup> She argues that time is foundational in the production of normalcy, such that engaging in particular behaviors at particular moments has become reified as the natural, common-sense course of human development. “Normative narratives of time,” in other words, “form the base of nearly every definition of the human in almost all of our modes of understanding, from the professions of psychoanalysis and medicine, to socioeconomic and demographic studies on which every sort of state policy is based, to our understandings of the affective and aesthetic.”<sup>48</sup> These normative narratives of time presume a linear development from a dependent childhood to an independent adulthood defined by marriage and reproduction.<sup>49</sup> Halberstam thus focuses most of her attention on how queer subcultures operate outside “the paradigmatic markers of life experience—namely, birth, marriage, reproduction, and death.”<sup>50</sup> In articulating queerness through temporality, Halberstam highlights “strange temporalities, imaginative life schedules, and eccentric economic practices.”<sup>51</sup> How might we read each of these categories of queer temporality in and through illness and disability?

Let’s begin with “strange temporalities”: Halberstam introduces her notion of queer time by talking about the early time of the AIDS epidemic, when “[s]ome gay men responded to the threat of AIDS . . . by . . . making community in relation to risk, disease, infection, and death.”<sup>52</sup> Although Halberstam does not limit queer time to the time of illness and infection, she describes it as “emerge[ing] from the AIDS crisis,” a context that forced gay communities to focus on “the here, the present, the now.” That focus, argues Halberstam, pushed gay communities out of more mainstream temporal logics, ones in which the future was not continually diminishing with each death, or each diagnosis, or each symptom.<sup>53</sup> Instead, the queer time of the epidemic deflects attention away from the future altogether, attending only to this moment, finding urgency in the present. By Halberstam’s reading, it was living, and dying, with AIDS



that pushed (some) gay men out of a normative life course and into queer ruminations on urgency and emergence. Given that Halberstam's iteration of queer temporality stresses illness as much as sex, one could certainly make the argument that the time of the epidemic is both queer and crip time.<sup>54</sup>

Tom Boellstorff offers "the time of coincidence" as another queer temporality, one in which time "falls rather than passes"; he refers here to the coincidence of two cycles of time, as in "May 23rd 'falls' on a Tuesday," finding in this concept of synchrony a way to move beyond strict linear time. It allows for two cycles of time (such as days of the week and numbers of the month) to be running simultaneously yet not perfectly parallel, creating circular moments of coincidence rather than straight (in both senses of the word) lines of forward movement.<sup>55</sup> Is it possible, though, to read more into this notion of "falling" time, a phrasing that suggests a modality more akin to stumbling, tripping, and impaired bodies than walking ones? What is the time of falling, and how might we read disability into this focus on coincidence, on simultaneity? Or how might we read the distinction between falling and passing time as a distinction between falling and passing in time?

I am reminded here of Eliza Chandler's meditation on falling on the sidewalk, her exploration of how tripping up her feet leads to tripping up categories of identification and disidentification. Falling on the sidewalk, she explains, becomes a moment of falling into disability; it is the falling that identifies her to others as disabled, plunging her into categories and identifications that trip her up. Falling makes passing impossible, even as she moves from one to the other moment by moment, even as she inhabits one category in her mind at the same time as she inhabits another in the eyes of others. The experience of falling in time leads Chandler to recognize how shame and pride coincide in her body on the sidewalk, a queer awareness of how her body falls into, exceeds, and fails expectations all at the same time.<sup>56</sup> It is, at least in part, this link between falling and failure that renders crip temporalities queer. Notions of failure and excess, and acts of failing to adhere to some societal norms while or by exceeding others, run throughout discussions of queer temporalities. Chandler knows that by falling she lives up to expectations about what *disability* does, even as she fails expectations about what the *body* does; failure and success thus coincide in the moment of falling.

We can move from "falling" to "falling ill" as another form of strange temporality. As Freeman herself suggests, living with illness can push time "out of joint," opening up alternative logics and orientations. Anthropologist Sarah Lochlann Jain explores how cancer diagnoses and prognoses interrupt "the idea of a time line and all the usual ways one orients oneself in time—one's age, generation, and stage in the assumed lifespan."<sup>57</sup> Living in "prognosis time" is thus a liminal temporality, a casting out of time; rather than a stable, steady progression through the stages of life, time is arrested, stopped. Paradoxically, even as the very notion of "prognosis" sets up the future as known and knowable, futurity itself becomes tenuous, precarious. But this

very precariousness can, as Halberstam finds in AIDS narratives, become an impetus for erotic investment in the present, in one's diagnosed body.

Laura Hershey reports that inadvertently learning the nature of her diagnosis—and, as a result, her prognosis—changed her whole orientation to the world; she was familiar with living with disability, but discovering her prognosis fundamentally altered her relationship to futurity, even though her body remained unchanged. Sitting alone at school, she ran across the definition of muscular dystrophy in the dictionary: "A genetic disorder in which the body's muscles weaken and eventually waste away." At that moment, she writes, "All the futures I had imagined for myself were now replaced by this newly-revealed, short future: 'eventually waste away.'"<sup>58</sup> For Hershey, the time of prognosis is a single moment of telling but also an extended, if not indefinite, period of negotiation and identification. During that period, past/present/future become jumbled, inchoate. The present takes on more urgency as the future shrinks; the past becomes a mix of potential causes of one's present illness or a succession of wasted time; the future is marked in increments of treatment and survival even as "the future" becomes more tenuous.<sup>59</sup>

The strange temporality of diagnosis/prognosis seems all the more dislocating, all the more dis- and reorienting, for those falling out of or exceeding diagnostic categories. How might we understand the experiences of those with chronic fatigue and chronic pain, or those with multiple chemical sensitivities (MCS), struggling for years to find a medical professional or social services provider to recognize their impairments? Or the veteran trying again and again to get the government to acknowledge and address the effects of Agent Orange or Iraq War Syndrome or PTSD?<sup>60</sup> "What is the 'time,'" in Christopher Nealon's framing, "of the repeated attempt?"<sup>61</sup> Nealon pushes here for an understanding of queer time that includes the temporal experiences of marginalization and disavowal; how, he wonders, is the repeated experience of being denied recognition an orientation to time?<sup>62</sup> His question reminds me of the stories and images in Rhonda Zwilling's powerful *The Dispossessed*, a profile of people with MCS who have lived through years of failed attempts to get their condition recognized, years that clearly took a toll; some of those Zwilling profiled ran out of time, ultimately committing suicide out of frustration and isolation. As Roberta S. puts it, "For the past 16 years I have lived in my car, traveling from place to place looking for a 'safe' place so I can be indoors. I am so worn out I think I will die soon."<sup>63</sup> With these stories in mind, I supplement Jain's "prognosis time" with the time of undiagnosis: the shuttling between specialists, the repeated refusal of care and services, the constant denial of one's experiences, the slow exacerbation of one's symptoms, the years without recognition or diagnosis, the waiting.

Thinking about diagnosis and undiagnosis as strange temporalities opens the door to still other framings of crip time, of illness and disability in and through time. What would constitute a temporality of mania, or depression, or anxiety? If we think of queer time as involving archives of rage and shame, then why not also panic attacks

or fatigue? How does depression slow down time, making moments drag for days, or how do panic attacks cause linear time to unravel, making time seem simultaneously to speed up and slam shut, leaving one behind?

"Strange temporalities" could then include the experiences of those with PTSD or MCS who live in a kind of anticipatory time, scanning their days for events or exposures that might trigger a response. Such scans include moving both forward and backward in time while remaining present in this moment: What has caused reactions before? What might cause reactions now? What reactions lie ahead? Writing about MCS, Mel Chen explains, "I now have a strategy of temporally placed imaginations; if my future includes places and people, I pattern-match them to past experiences with chemically similar places and chemically similar people."<sup>64</sup> Surviving with MCS requires an embodied awareness of one's location in space and time, "turning toward . . . or correspondingly away from" other bodies in the desire to survive from this moment into the next.<sup>65</sup> This time of anticipation is itself a kind of queer liminality, living always in anticipation of the moment that has not yet arrived: the rogue fragrance, the invisible gas, the passing smoke. Queer, too, in that it requires, and is born of, an erotic attachment to the surrounding environment. Chen writes poignantly about how this temporality of anticipation and response fosters queer orientations to objects and people: her sofa—familiar, safe—becomes more present, more of a home to her body than the bodies of others, while people—with their unexpected, undesired fragrances and smokes—become foreign, disorienting.<sup>66</sup> Encountering them in real time means being exposed to their chemical pasts (the shampoo they used that morning, the cigarette they smoked after class), which then impact one's immediate future (feeling fatigue, fog, nausea). MCS, then, leads to a strange temporality, one of coincidence and multiplicity. The constantly forward-looking stance, the stance of anticipation, is, of necessity, bound also to the constant glance back. Chen experiences her present body in relation to past exposures, with both determining how future not-yet exposures will play out. The strange temporalities of MCS thus include not only Chen but also those around her, offering glimpses of how our individual choices can affect the temporalities of others; I can unwittingly, unknowingly, cast someone else out of time by my chemical consumption.<sup>67</sup>

And what of Halberstam's "imaginative life schedules"? I think here of those crip families who juggle attendant care, receiving hours for one person but unofficially using them for another. For example, one adult might be "more" disabled in the eyes of the state and therefore qualify for more hours than her lover; once in the home, however, an attendant might do work that benefits the lover, or their children. Or what about the very scheduling of attendant care itself and the ways in which it requires a simultaneous inhabiting of present and future? Harriet McBryde Johnson explains that working with attendants requires scheduling "in advance each bathroom trip, each bath, each bedtime, each laying out of our food and . . . books, each getting in and out of our chairs."<sup>68</sup> The immediate future then mixes with the present, as Johnson

uses this moment to plan the next and the next and the next. On one level, this kind of scheduling is more a difference in degree than in kind to the planning everyone does, regardless of attendant care. At another level, though, it requires a different orientation to one's body, a foregrounding of physical needs—eating and sleeping and shitting—and the ways in which they shape our days. It is a literal projecting of one's body *as a body* into the future even as one inhabits one's body in the present. What orientations to space and time might this embodied dualness allow?

Indeed, this kind of anticipatory scheduling is not limited to working with attendants, but often extends to working with and in one's own mind/body. For those who live with chronic fatigue or pain, for example, the present moment must often be measured against the moment to come: if I go to this talk now, I will be too tired for that class later; if I want to make that show tomorrow night, I need to stay home today.<sup>69</sup> This idea of conserving energy, of anticipating, can be read as queer in that it bucks American ideals of productivity at all costs, of sacrificing one's body for work. In other words, how might we begin to read these practices of self-care not as preserving one's body for productive work but as refusing such regimes in order to make room for pleasure?

"Eccentric economic practices," Halberstam's third category, can then include this kind of refusal of productivity; it might also include the many disabled people who operate on the barter system, trading services and products below the radar of the state. Attendant services, health care, and disability payments often come with strict requirements about how much one can earn and still receive services, an amount that keeps many disabled people hovering near the poverty line. Eccentric economic practices can ease some of the financial pressure while also enabling crips to write or create without putting their health care in jeopardy. We can think here, too, of disabled people who create their own cooperatives and collectives of attendant care, negotiating their own terms apart from the requirements of the state.

Imagining these kinds of practices brings me right back to Halberstam and her articulation of queers as those who

will and do opt to live outside of reproductive and familial time as well as on the edges of logics of labor and production. By doing so, they also often live outside the logic of capital accumulation: here we could consider ravers, club kids, HIV-positive barebackers, rent boys, sex workers, homeless people, drug dealers, and the unemployed. Perhaps such people could productively be called "queer subjects" in terms of the ways they live (deliberately, accidentally, or of necessity) during the hours when others sleep and in the spaces (physical, metaphorical, and economic) that others have abandoned, and in terms of the ways they might work in the domains that other people assign to privacy and family.<sup>70</sup>

This definition, too, could easily be applied to disability, rendering disabled people "queer subjects." Most immediately we can recognize that disability likely inhabits the categories named here: many disabled people are homeless and unemployed/underemployed; HIV falls under the rubric of illness and disability, as does drug addiction; and



disability does not preclude one from being a sex worker (and may, in fact, facilitate it or compel it). Moreover, as I noted above, the mechanisms of state services certainly push one out of the logic of capital accumulation and onto the edges of labor and production.

But we can think, too, of the blurring of boundaries between public and private. How does the use of attendants to assist with dressing and toileting disrupt the binary between private and public? Or what of the disabled people who use paid attendants to assist them with sex, either by positioning them in bed with their partners or by setting up and turning on sex toys? Or what of disabled people who engage in sex with their attendants? Each of these practices involve paid work “in the domains that other people assign to privacy and family,” suggesting at the very least productive overlaps between queerness and disability.

Ellen Samuels explores this possibility of crip time as resistant orientation: “Crip time refuses to define itself in terms of either the ideal or the average: Schedules for work, parenting, and the social are thus shaped by individual needs, desires, and abilities, rather than by regimented economic and cultural imperatives.”<sup>71</sup> By attending to the individual and the private, Samuels paradoxically indexes the social and the public; to refuse the regimentation of economic imperatives across the terrain of one’s body, or one’s time, is to reimagine what public time and social relations can look like. “Eccentric economic practices” challenge the normative modalities that define time, such as productivity, accomplishment, and efficiency, and they urge us toward something different.<sup>72</sup>

### On Longevity, Lost History, and Futurity

Crip and queer temporalities clearly overlap, but reading them in relation to each other reveals areas of disconnect as well. In this third section, I highlight two ways that disability seems to exceed queer temporalities: first, the oppositional relationship between queer time and longevity; and second, the queer desire for reformulated histories. Early in Halberstam’s definition of queer time, on one of the first pages of *In a Queer Time and Place*, she laments that “we create longevity as the most desirable future, applaud the pursuit of long life (under any circumstances), and pathologize modes of living that show little or no concern for longevity.”<sup>73</sup> This critique appears again, almost verbatim, in the book’s conclusion, thereby bookending Halberstam’s depiction of queer time and alternative temporalities.<sup>74</sup> Although she never explicitly explores the notion of longevity in depth, its appearance at defining moments in the text suggests that her understanding of queer time draws its meaning, at least in part, from its opposition to longevity.

At first blush, this claim resonates; challenging the fetishization of longevity seems essential to both queer and crip politics, both queer and crip theory. Halberstam first issues this challenge in her discussion of HIV/AIDS and its effects on gay communities. As we saw earlier, she frames the time of the epidemic as a temporality that

refuses futurity, one prompted by gay men who had been forced by death and disease to rethink the cultural focus on living long lives. No longer able to project their young selves far into the future, they were compelled to live for the moment, this moment, in all of its urgency, the future be damned.<sup>75</sup> I hear this call as an equally crip move: we can certainly read “longevity” as a code for both “health” and “stability,” two terms disability studies is invested in troubling. I think, for example, of activists such as Hershey, who lived most of their lives knowing that a long life span was not in their future, but saw that fact as a call for love and justice rather than a sign of tragedy or shame. Or, as Robert McRuer argues in his queercrit reading of performance artist Bob Flanagan, “[S]urviving well can paradoxically mean surviving sick”; longevity is not the only rubric that matters.<sup>76</sup> A critique of longevity, then, can be easily articulated through disability studies; the devaluation of disabled bodies is due in no small part to those bodies’ failure to adhere to norms of bodies as unchanging, impermeable, long-lasting, and stable.

This is not the only crip reading of this text, however; it bumps up against another possible reading of this passage, one that opposes queer time not only to longevity but to disability. Reading again, “[W]e create longevity as the most desirable future, applaud the pursuit of long life (under any circumstances), and pathologize modes of living that show little or no concern for longevity.”<sup>77</sup> What is a crip to do with that troubling parenthetical? The insertion of “(under any circumstances)” seems to signal anxieties about illness, physical and mental degeneration, and disability: I read “under any circumstances” and hear “extraordinary measures,” “breathing through a machine,” “dependent on others.” I read “under any circumstances” and hear “better off dead” and “life not worth living.” Halberstam’s lack of specificity about what she means by “long life (under any circumstances)” and “longevity” suggests an assumption of shared meaning or common understanding; apparently, we all know which circumstances would render life not-queer.

Halberstam undercuts her own arguments here, allowing culturally embedded fears of age, illness, and disability to dilute her critique. Thinking through disability suggests that at the very least we do *not* value longevity under any circumstances or by any means necessary; we do, indeed, “pathologize modes of living that show little or no concern for longevity,” but one such mode of living is those bodies/minds who insist on living “under any circumstances.” A critique of longevity can begin to feel misplaced in a culture that continually supports cutting services to disabled poor people, and that continues to warehouse disabled people in institutions and nursing homes, two practices that very well may ensure those disabled people do not live long lives.

Halberstam herself recognizes that the “hopeful reinvention of conventional understandings of time,” as in her articulation of the time of the epidemic, is more possible for some bodies—and, we might add, some populations—than others.<sup>78</sup> Drawing on the work of Cathy Cohen, she notes, “[S]ome bodies are simply considered ‘expedient,’ both in mainstream and marginal communities, and the abbreviated life spans

of black queers or poor drug users, say, does not inspire . . . metaphysical speculation on curtailed futures, intensified presents, or reformulated histories.<sup>79</sup> In focusing so closely on Halberstam's dismissal of a "concern for longevity" and "long life (under any circumstances)," I am insisting that we see disability—and more importantly, *living* with a disability, or living as disabled—as one of the positions that needs attention here. I argue for a disability studies that sees both "black queers" and "poor drug users" as within its purview, precisely because of their depiction as expendable, so I want to be clear that I am not suggesting a mere substitution of "disabled people" for "black queers or poor drug users" in Halberstam's quote. Rather, reading her queer critique of longevity through the lens of institutionalization—a lens which can encompass "disabled people" right alongside "poor drug users" and "black queers"—has a similar effect: "curtailed futures" sounds a lot less romantic, a lot less queer, when we think through the precise circumstances under which we do, and do not, fetishize longevity. So, too, can the focus on "reformulated histories." The reimagining of lost pasts, or the conjuring of imagined pasts, animates much recent queer theory on time and futurity. Queer philosopher Shannon Winnubst, for example, urges an imagining of "lost pasts, where meanings and discourses are contested and practices and pleasures are forged."<sup>80</sup> As with critiques of longevity, her call to lost pasts can be deployed provocatively for crip ends. I think, for example, of Georgina Kleege and Brenda Brueggemann writing letters to the dead, not only contesting histories (of Helen Keller and Mabel Hubbard Bell, respectively) and the meanings attributed to them but refusing boundaries of place and time.<sup>81</sup> Writing open letters to the dead can surely be read as a queer crip interruption of the linear time of past/present/future as separate and distinct planes.<sup>82</sup> Kleege inserts herself into Keller's frame, arguing with her, disputing her accounts, imagining alternate endings: in so doing, she contests mainstream sentimental accounts of both Keller and of disabled people more generally, presenting the past (rather than the future) as a viable and necessary site for politics, for rage, and for pleasure.

And yet, this reimagining of lost pasts can bleed easily into a normalizing nostalgia; Muñoz warns of the difference between "queer utopian memory" (such as Winnubst's "lost pasts") and the desire for "a nostalgic past that perhaps never was."<sup>83</sup> Thinking through crip temporalities and futurities requires, then, a grappling with nostalgia, a recognition of the powerful role nostalgia plays in approaches to the body. Indeed, fears about longevity "under any circumstances"—fears of disability, in other words—are often bound up in a kind of *compulsory nostalgia* for the lost able mind/body, the nostalgic past mind/body that perhaps never was.

People with "acquired" impairments, for example, are described (and often describe themselves) as if they were multiple, as if there were two of them existing in different but parallel planes, the "before disability" self and the "after disability" self (as if the distinction were always so clear, always so binary). Compulsory nostalgia is at work here, with a cultural expectation that the relation between these two selves is

always one of loss, and of loss that moves in only one direction. The "after" self longs for the time "before," but not the other way around; we cannot imagine someone regaining the ability to walk, for example, only to miss the sensation of pushing a wheelchair or moving with crutches. Contrast this nostalgia for the (imagined) nondisabled body with the before-and-after imagery in weight-loss advertisements. As Le'a Kent argues, "The before-and-after scenario both consigns the fat body to an eternal past and makes it bear the full horror of embodiment, situating it as that which must be cast aside for the self to truly come into being."<sup>84</sup> Elena Levy-Navarro extends Kent's argument, describing fat people as "history itself—that is, they are the past that must be dispensed with."<sup>85</sup> Fat bodies and disabled bodies appear in different temporal frames here, but neither is permitted to exist as part of a desired present or desirable future.

This assumption that disability cannot be a desirable location, and that it must always be accompanied by a nostalgia for the lost able mind/body, is what animates "the cure question" so familiar to disabled people: Wouldn't you rather be cured? Wouldn't you like to be as you were before? Wouldn't you prefer to be nondisabled?<sup>86</sup> The repetition of the question, the fact that disabled people are consistently expected to address it, is part of what gives the question its strength, its compulsory and coercive power. It has become inescapable, and the answer is assumed to be self-evident.

Yet, as Susan Wendell explains, such positionings are rarely so straightforward. In the same breath that she wishes for a cure to her chronic fatigue and pain, she notes that a complete return to her "before" state would lead to "dissonance": "I cannot wish that I had never contracted ME [myalgic encephalomyelitis], because it has made me a different person, a person I am glad to be, would not want to have missed being, and could not imagine relinquishing, even if I were 'cured!'"<sup>87</sup> Wendell works to inhabit both the before and the after at once, refusing the bifurcation of her identity into two distinct temporal planes.

But even those who have been disabled since birth are confronted with questions of temporal longing, expected to mourn what they never had. Eli Clare refuses this notion of the lost and longed-for body, this alleged desperation to return: "[F]or me having CP [cerebral palsy] is rather like having blue eyes, red hair, and two arms. I don't know my body any other way."<sup>88</sup> This presumption of loss, one that extends even to people who never "possessed" what they allegedly "lost," is a symptom of the compulsory able-bodiedness/able-mindedness challenged by disability studies scholars and activists. It illustrates the extent to which the nondisabled body/mind is the default position, as if all bodies/minds are purely abled until something happens to them, as if mind/body variation were not a common occurrence. We are expected to take up nostalgic positions toward our former selves, mourning what we have lost and what can now never be.

Thus the lost pasts I mention here—lost able-bodies, lost able-minds—are not queer but hypernormative; they rely on an assumption that all disabled people long for a lost whole, pre-illness, pre-disability body. In this framing, illness and disability



can, and should, be left behind; these lost pasts are compulsorily hypernormative in that they are presented as futures disabled people would give anything to inhabit. Past, present, and future each become vexed, fraught: we lost what we had in the past, we exist in a present consumed by nostalgia for that loss, and we face futures far unlike the ones we had previously imagined. The futures we now face are then both unimaginable and unimaginable, inconceivable. Compulsory nostalgia figures these futures as futures no one could possibly want; they have always already failed to achieve the ideal normalcy of our (imagined) able-bodied/able-minded pasts. The only culturally acceptable—culturally recognizable—future in this context is a curative one, one that positions a medicalized cure as just around the corner, as arriving any minute now. But this kind of cure-driven future positions people with disabilities in a temporality that cannot exist fully in the present, one where one's life is always on hold, in limbo, waiting for the cure to arrive. Catherine Scott traces a version of this limbo in Christopher Reeve's memoirs, describing them as a "struggle between the longed-for past, the painful present, and the hoped-for future."<sup>90</sup>

Returning to Halberstam's caution that "the abbreviated life spans of black queers or poor drug users . . . does not inspire . . . metaphysical speculation on curtailed futures, intensified presents, or reformulated histories," how might we respond not by refusing such speculations altogether but by revising them, expanding them?<sup>91</sup> How might the life and times of "black queers or poor drug users" or disabled people lead to temporal understandings quite different from the ones sketched out in *No Future* or *In a Queer Time and Place* or *Feminist, Queer, Crip*, but still quite queer? What is the time of incarceration, an experience known as "doing time," or the time of institutionalization, fates familiar to the two populations Halberstam names here? Both institutionalization and incarceration are defined through overlapping temporal frames: *temporarily* committed, *permanently* placed, *consecutive life* sentences; both raise questions of chronology and development, such as the treatment of juveniles as adults (in prisons) and of young(er) adults as elderly ones (in nursing homes). How then do our/my notions of crip time shift if we/I think not only of institutionalization but also of incarceration as a sign of disability oppression?<sup>92</sup>

Or, returning to Nealon's notion of the "repeated attempt," how do our metaphysical speculations change if we see antiracist interruptions of monolithic whiteness as moments in and of queer time? Or what if I were to take seriously Chen's insistence that "the time of recovery" includes the time it takes to recover from a racist encounter on the street as much as the time it takes to recover from a chemical exposure, with both temporalities constitutive of and important to crip time?

These questions are, for me, bound up in questions of analogy and experience, romanticism and metaphor. How can I articulate a queercrip time that does not oppose queerness to longevity yet maintains a critical stance toward hegemonic expectations of (re)productivity? Or, to put it differently, how do I respond to the fact that the theories we deploy, the speculations we engage, play out across different bodies differently?<sup>93</sup>

## Future Desires, Present Despair

I have written this book because I desire crip futures: futures that embrace disabled people, futures that imagine disability differently, futures that support multiple ways of being. I use this language of desire deliberately. I know how my heart can catch when I see a body that moves oddly or bears strange scars. I know how my body shifts, leans forward, when I hear someone speak with atypical pauses or phrasing, or when talk turns to illness and disability. Part of what I am describing is a just born of recognition, a just to see bodies like my own or like the bodies of friends and lovers, as well as a hope that the other finds such recognition in me.<sup>94</sup> Perhaps most important to this examination of disability futures, it is a desire born largely of absence. We lack such futures in this present, and my desires are practically inconceivable in the public sphere. There is no recognition that one could desire disability, no move to imagine what such desire could look like.<sup>95</sup>

In 1989 Eve Kosofsky Sedgwick lamented the cultural pervasiveness and acceptance of "the wish that gay people *not exist*." "There are many people in the worlds we inhabit," she explains, "who have a strong interest in the dignified treatment of any gay people who may already happen to exist. But the number of persons or institutions by whom the existence of gay people is treated as a precious desideratum, a needed condition of life, is small." The notion that someone could dispense "advice on how to help your kids turn out gay" is almost inconceivable, but, she warns, oppression will continue until we can both imagine and experience people and institutions doing exactly that.<sup>96</sup> What we desperately need is "a strong, explicit, *erotically invested* affirmation of some people's felt desire or need that there be gay people in the immediate world."<sup>96</sup>

I have avoided the temptation to substitute "disabled" for gay in the preceding quote, partly because I want to avoid any suggestion that Sedgwick's desire is now mere history. There are unfortunately far too many ways in which 2012 does not look that different from 1989. But I also worry about the other dangers of substitutive logics and practices, such as the rhetorical erasure of people inhabiting both locations, of queers with disabilities. More to the point, such easy paralleling fails to tease out the specificities of the queer/disability relationship. Facile parallels or quick substitutions make it more difficult to recognize how queerness continues to be read through the lens of disability, with both queers and crips rendered unnatural, sick, degenerate, and deviant. (This reading seems especially common for people on the trans spectrum or for intersex folks.) I use the quote here because it still feels all too true in 2012, and I, too, long for that kind of embodied investment in queer lives. I use it, too, because I think the inability to value queer lives is related to the inability to imagine disabled lives. Both are failures of the imagination supporting and supported by the drive toward normalcy and normalization. Not wanting to cultivate queerness, or to build institutions supporting that kind of cultivation, is intertwined with fears about cultivating disability. (I have a hard time even typing "cultivating disability" because it



is almost impossible to imagine what a just version of that would look like. This book serves as my attempt.)

Thus my desire for crip futures is, as Heather Love puts it, “a hope inseparable from despair.”<sup>97</sup> I feel this hope—and the hope has the fierce intensity that it does—because it is birthed out of and coexists with this despair about our impoverished imaginations. What I need is to follow some of these longings out, even if they put me in the realm of fantasy. Changing our imaginations, suggests Judith Butler, allows us to change our situations. Fantasy carries a “critical promise,” she argues, “allow[ing] us to imagine ourselves and others otherwise.”<sup>98</sup>

This intermingling of recognition and absence, of despair and hope, renders my desire quite queer. Queer in that my want, my longing, my pleasure intensifies with the queerness of these crip bodies, these crip futures. Queer, too, in that in imagining crip futures, I mean more than particular, identifiable bodies. I mean possibility, unpredictability, promise: the promise of recognizing crip where I did not expect to find it, the possibility of watching “crip” change meanings before my eyes. I name this desire “queer” in part because of its ambiguity. Becoming more “visible”—by increasing and publicizing the presence of disabled people in public, perhaps—does not guarantee acceptance or inclusion, especially for those not already privileged by race and class.<sup>99</sup> As feminists from Minnie Bruce Pratt to Bernice Johnson Reagon to Chandra Talpade Mohanty have cautioned, the desire for home, for familiarity, often leads to naïve evocations of community.<sup>100</sup> Thus, in naming and experiencing this desire, I am likely misreading and miscognizing the bodies and practices of others. I am, in other words, finding both disability and desire where they don’t necessarily belong—surely a potentially queer and crip move.

This desire, these imaginings, cannot be separated from the crip pasts behind us or the crip presents surrounding us; indeed, these very pasts and presents are what make articulating a critical crip futurity so essential. To put it bluntly, I, *we*, need to imagine crip futures because disabled people are continually being written out of the future, rendered as the sign of the future no one wants. This erasure is not mere metaphor. Disabled people—particularly those with developmental and psychiatric impairments, those who are poor, gender-deviant, and/or people of color, those who need atypical forms of assistance to survive—have faced sterilization, segregation, and institutionalization; denial of equitable education, health care and social services; violence and abuse; and the withholding of the rights of citizenship. Too many of these practices continue, and each of them has greatly limited, and often literally shortened, the futures of disabled people. It is my loss, our loss, not to take care of, embrace, and desire all of us. We must begin to anticipate presents and to imagine futures that include all of us. We must explore disability in time.

## 2 At the Same Time, Out of Time

Ashley X

The stories of women with disabilities must be told, not as stories of vulnerability, but as stories of injustice.

—Sherene Razack, “From Pity to Respect”

IN THINKING ABOUT crip futurity, I find myself haunted by Ashley X. Born in 1997, the girl known as Ashley X was diagnosed with “static encephalopathy” a few months after her birth. “In the ensuing years,” doctors note, “her development never progressed beyond that of an infant,” and her doctors held no hope that her cognitive or neurological baseline would improve.<sup>1</sup> “At the age of 6 years, she [could] not sit up, ambulate, or use language.”<sup>2</sup> Concerned about their daughter’s long-term future, Ashley’s parents met with doctors in 2004 to discuss the potential effects of puberty and physical growth on their ability to care for her at home. Together they crafted a two-pronged plan: “attenuate” Ashley’s growth by starting her on a high-dose estrogen regimen; and, prior to the estrogen treatment, remove Ashley’s uterus and breast buds in order “to reduce the complications of puberty” and mitigate potential side effects of the estrogen treatment.<sup>3</sup> According to her parents and doctors, these interventions were necessary for Ashley’s future quality of life: they would reduce her pain and discomfort (by removing the possibility of her menstruating or developing breasts) and would enable her parents to continue caring for her at home (by keeping her small enough to turn and lift easily). Her parents worried that, without the Treatment, Ashley would become too cumbersome for them to lift safely, and, as a result, her participation in social and recreational activities would decrease dramatically.<sup>4</sup> Ashley’s doctors took this concern a step further, expressing fear that caring for her at home might eventually become “untenable” and that Ashley’s parents would need to place her “in the hands of strangers.”<sup>5</sup>

families do not always have the information they need to make reproductive decisions about disability, and that stereotypes about disability persist, we do not think the response to that situation is to oppose assisted reproductive technologies or limit women's rights.

The recent statements by British advice columnist Virginia Ironside about the "suffering" of disabled children similarly require a challenge from disability and reproductive rights supporters. In arguing for the right to abortion, Ironside stated that knowingly giving birth to a child with disabilities is cruel, and that in such cases abortion is the "moral and unselfish" response. She added that if she had a sick or disabled child, she would not hesitate to "put a pillow over its face," as would "any loving mother." Although Ironside's comments about infanticide have been rightly condemned, her assertion that abortion is the only proper response to disability has prompted little controversy, as has her assumption that advocacy for abortion rights requires accepting the construction of disability as unrelenting tragedy. As reproductive rights advocates who are committed to disability rights, we refuse to accept the rhetorical use of disability as an argument for abortion rights. Reproductive rights demands not only access to abortion but also the right to have children, including children with disabilities, access to information about parenting, and the social and economic supports to parent all children with dignity.

In other words, we hold both disability rights and reproductive rights together, refusing arguments for women's reproductive autonomy that deny disability rights, and refusing arguments for the human rights of people with disabilities that deny the right of women and families to make the best reproductive decisions for themselves.

Although our statement is motivated by these events, we recognize that these are only the most recent manifestations of long-standing prejudices against people with disabilities and of the use of disability stereotypes to undermine women's and families' reproductive autonomy and access to abortion. We hope, with this statement, to support other activists and scholars who are equally committed to both reproductive rights and disability rights. We hope that as advocates in movements that share similar values around civil and human rights we can continue to speak out against the use of reproductive rights to undermine disability rights and the use of disability rights to undermine reproductive rights. Reproductive rights and disability rights are intertwined.

In solidarity,

Julia Epstein  
Laura Hershey  
Sujatha Jesudason  
Alison Kafer  
Dorothy Roberts  
Silvia Yee

October 15, 2010

## Notes

### Introduction

1. Michael Gerson, "The Eugenics Temptation," *Washington Post*, October 24, 2007, A19.
2. I have borrowed my phrasing here from Ruth Hubbard. See her "Abortion and Disability: Who Should and Who Should Not Inhabit the World?" in *The Disability Studies Reader*, ed. Len-

nard J. Davis (New York: Routledge, 2006), 93-103. For an overview of Watson's career by one of his former assistants, see Charlotte Hunt-Grubbe, "The Elementary DNA of Dr. Watson," *Sunday Times* (UK), October 14, 2007. In that article, Watson laments that "all our social policies are based on the fact that [Africans'] intelligence is the same as ours—whereas all the testing says not really." He has been quoted elsewhere as supporting the abortion of fetuses that contain "the gay gene," if such tests eventually become possible, although he later claimed he was simply defending women's right to choose under any circumstances. V. MacDonald, "Abort Babies with Gay Genes, Says Nobel Winner," *Telegraph* (UK), February 16, 1997; Steve Boggan and Glenda Cooper, "Nobel Winner May Sue over Gay Baby Abortion Claim," *Independent* (UK), February 17, 1997; and Richard Dawkins, "Letter: Women to Decide on Gay Abortion," *Independent* (UK), February 19, 1997.

Watson is often described as a provocateur, willing to put things in the most shocking way to make a point, and, as a result, it is tempting to dismiss his comments as extreme and isolated. But his personal penchant for the outrageous doesn't change the fact that many of his assumptions, particularly about disability, are quite pervasive. The filing of wrongful birth suits would be another manifestation of this notion that no one wants disabled children; in these suits, parents sue their doctors for failing to catch disabling conditions in utero and thereby preventing them from aborting the fetus. I discuss the issue of disabled children and reproduction in chapters 3 and 7.

3. In his deployment of "crazy," Watson employs the same kind of "common sense" logic he uses regarding Down syndrome: in this framework, "obviously" both conditions are undesirable and irredeemable. Part of my project in this book, then, is to work to counteract this assumption about both mental illness and cognitive disabilities. That work occasionally involves occupying and reimagining epithets like "crazy."
4. Monica J. Casper and Lisa Jean Moore, *Missing Bodies: The Politics of Visibility* (New York: New York University Press, 2009), 4.

5. Although disability theorist Tom Shakespeare and journalist Norah Vincent hold opposing views about the worth and need for disability studies (with Shakespeare "for" and Vincent "against"), they share the belief that casting disability as desirable leads, logically, to the belief that we can intentionally disable other people. Vincent suggests, for example, that adhering to such a position must mean that one is opposed to giving pregnant women access to folic acid because it decreases the incidence of certain impairments. Shakespeare argues that "if impairment were just another difference"—not negative but neutral—"there would be nothing wrong with painlessly altering a baby so they could no longer see, or could no longer hear, or had to use a wheelchair." Contrast their position with that of Nirmla Erevelles, who argues that a critical disability response to the question of desiring disability is not to deny such a possibility but rather to explore the social and material conditions under which such desire is possible. Nirmla Erevelles, *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic* (New York: Palgrave Macmillan, 2011), 29. Tom Shakespeare, *Disability Rights and Wrongs* (London: Routledge, 2006), 64; Norah Vincent, "Enabling Disabled Scholarship," *Salon*, August 18, 1999, <http://www.salon.com/books/1999/08/18/disability/index.html>.

6. For an account of disability as human biodiversity, see Rosemarie Garland-Thomson, "Welcoming the Unbidden: The Case for Preserving Human Biodiversity," in *What Democracy Looks Like: A New Critical Realism for a Post-Seattle World*, ed. Amy Schrager Lang and Cecelia Tichi (New Brunswick, NJ: Rutgers University Press, 2006), 77–87. See also Kenny Fries, *The History of My Shoes and the Evolution of Darwin's Theory* (New York: Carroll & Graf, 2007).
7. Although most simulation exercises focus on mobility-impairment/wheelchairs and blindness/blindfolds, I have heard of exercises employing deafness/noise-canceling headsets and, astonishingly, speech impairment/marbles (i.e., asking students to try to speak with marbles in their mouths). Other disabilities, however, seem beyond the reach of these exercises. There are not simulations, for example, of chronic illness, pain, or fatigue, perhaps because people already know what those sensations feel like. I suspect simulations are limited to those conditions that sound fun to experience because they come with props or accoutrements, e.g., canes and wheelchairs. Mental disability and multiple chemical sensitivities are less visible and perhaps therefore more frightening; it would be harder to know when the simulation was beginning and ending, thereby interrupting the distancing dynamic on which these exercises ultimately rely. Some impairments are harder to take on and off.
8. Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008), 29. For another critique of disability simulation exercises, see Art Blaser, "Awareness Days: Some Alternatives to Simulation Exercises," *Ragged Edge Online*, September/October 2003, <http://www.ragged-edgemagazine.com/0903/0903fr.html>.
9. Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998), 11.
10. Nor do all medical professionals employ an individual/medical model of disability; service providers are also often allies and activists, and there certainly are medical professionals who themselves have disabilities. Thus, as Leslie J. Reagan notes, "[t]he disabilities critique of the medical model . . . perhaps may be best understood as a critique of the entire society, rather than of the medical profession alone, for prioritizing medicine and medical solutions over social reconstruction." Leslie J. Reagan, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010), 65.
11. Denis Dutton, "What Are Editors For," *Philosophy and Literature* 20 (1996): 551–66, accessed September 24, 2009, [http://www.denisdutton.com/what\\_are\\_editors\\_for.htm](http://www.denisdutton.com/what_are_editors_for.htm); emphasis in original.
12. To clarify this point, Dutton provides a list of the symptoms of cretinism: "The bodily symptoms (including limb stunting, enlarged lips, open, drooling mouth, broad, flat face, sallow skin, etc.), and intellectual subnormality to the level of imbecile or moron, are actual medical conditions." Dutton, "What Are Editors For."
13. Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory," in *Gendering Disability*, ed. Bonnie Smith and Beth Hutchinson (New Brunswick, NJ: Rutgers University Press, 2004), 77.
14. For one of the most well-known examples of this phenomenon, see Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996).
15. Jim Swan, "Disabilities, Bodies, Voices," in *Disability Studies: Enabling the Humanities*, ed. Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland-Thomson (New York: Modern Languages Association, 2002), 293.
16. Shakespeare suggests that the focus on the medical model as the main site for disability critique is misguided; "when closely analyzed, it is nothing but a straw person" because no one actively and explicitly argues for such an approach to disability. Although I agree that a notion of "the" medical model is unnecessarily simplistic and reductionist—medical approaches to disability are not monolithic, and many service providers support social change on top of any medical treatments—medical constructions and definitions of disability, impairment, and disabled bodies/minds remain the most culturally pervasive frameworks. Shakespeare, *Disability Rights and Wrongs*, 18.
17. Janet Price and Margrit Shildrick, "Uncertain Thoughts on the Disabled Body," *Vital Signs: Feminist Reconfigurations of the Bio/Logical Body*, ed. Margrit Shildrick and Janet Price (Edinburgh: Edinburgh University Press, 1998), 243, 246.
18. B. J. Gleeson, "Disability Studies: A Historical Materialist View," *Disability and Society* 12, no. 2 (1997): 193. See also Shakespeare, *Disability Rights and Wrongs*.
19. Wendell, *Rejected Body*, 14. See also Shelley Tremain, "On the Subject of Impairment," in *Disability/Postmodernity: Embodiment Political Theory*, ed. Mairian Corker and Tom Shakespeare (New York: Continuum, 2002), 32–47.
20. See, for example, Adrienne Rich, "Notes Toward a Politics of Location," *Blood, Bread, Poetry: Selected Prose, 1979–1985* (New York: W. W. Norton, 1994): 210–31.
21. Nor, suggests Michael Bérubé, can the social model adequately address cognitive or intellectual impairments; although social and structural changes are both necessary and long overdue, "it's possible that [a] cognitively impaired person . . . would be impaired by any built environment." Michael Bérubé, "Term Paper," *Profession* (2010): 112. For other recent critiques of the social model, particularly its foreclosure of certain questions from debate, see Julie Livingston, "Insights from an African History of Disability," *Radical History Review* 94 (Winter 2006): 111–26; Anna Mollow, "When Black Women Start Going on Prozac: Race, Gender, and Mental Illness in Merti Nana-Ama Danguah's *Willow Weep for Me*," *MELUS* 31, no. 3 (2006): 67–99; Anna Mollow and Robert McRuer, introduction to *Sex and Disability*, ed. Robert McRuer and Anna Mollow (Durham, NC: Duke University Press, 2012), 1–34; and Shakespeare, *Disability Rights and Wrongs*.
22. Liz Crow, "Including All of Our Lives: Renewing the Social Model of Disability," in *Encounters with Strangers: Feminism and Disability*, ed. Jenny Morris (London: The Women's Press, 1996), 210. For sharp analyses and moving insights on the importance of trauma and depression to radical projects—what Heather Love calls "feeling backward"—see Ann Cvetkovitch, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Durham, NC: Duke University Press, 2003); and Heather Love, *Feeling Backward: Loss and the Politics of Queer History* (Cambridge, MA: Harvard University Press 2007).
23. Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, 2nd ed., ed. Lennard J. Davis (New York: Routledge, 2006), 199.
24. Dutton uses race as his primary example, arguing that there can be no disability equivalent to the "Black is Beautiful" movement of the 1960s.
25. Simone Chess, Alison Kater, Jessi Quizar, and Mattie Udora Richardson, "Calling All Restroom Revolutionaries!" in *That's Revolting! Queer Strategies for Resisting Assimilation*, ed. Matt Bernstein Sycamore (New York: Soft Skull, 2004), 189–206. I discuss PISSAR in more detail in chapter 7.
26. Chantal Mouffe, *The Return of the Political* (London: Verso, 1993), 3.
27. Jodi Dean, "Introduction: The Interface of Political Theory and Cultural Studies," in *Cultural Studies and Political Theory*, ed. Jodi Dean (Ithaca, NY: Cornell University Press, 2000), 6.
28. Dean, "Introduction: The Interface of Political Theory," 4; emphasis mine.
29. For an examination of ableism, see Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York: Palgrave Macmillan, 2009). On compulsory able-bodiedness, see Robert McRuer, "Compulsory Able-Bodiedness and Queer/Disabled Existence," in *Disability Studies: Enabling the Humanities*, ed. Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland-Thomson (New York: Modern Language Association, 2002): 88–99; and Alison Kater, "Compulsory Bodies: Reflections on Heterosexuality and Able-bodiedness," *Journal of Women's History* 15, no. 3 (2003): 77–89.
30. Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2009), 280.
31. For other critical accounts of disability identity, see Gloria Anzaldúa, "Disability and Identity," in *The Gloria Anzaldúa Reader*, ed. Analouise Keating (Durham, NC: Duke University Press,



2009), 298–302; Robert McKuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006); Anna Mollow, "Identity Politics and Disability Studies: A Critique of Recent Theory," *Michigan Quarterly Review* 43, no. 2 (2004): 269–96; and Mollow and McKuer, introduction to *Sex and Disability*.

32. Ben Pitcher and Henriette Gunkel, "Q&A with Jasbir Puar," *darkmatter Journal*, accessed December 3, 2009, <http://www.darkmatter101.org/site/2008/05/02/q-a-with-jasbir-puar/>.

33. Joan W. Scott, "Cyborgian Socialists?" in *Coming to Terms: Feminism, Theory, Politics*, ed. Elizabeth Weed (New York: Routledge, 1989), 216.

34. Linton, *Claiming Disability*, 4, emphasis mine.

35. The field of philosophy has a fair number of texts dealing with cognitive impairments, partly because of the importance of, and discourses around, rationality in the field. Disability studies approaches to these topics within the field, however, remain quite rare. For exceptions, see, for example, Licia Carlson, "Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation," *Hypatia* 16, no. 4 (2001): 128–33; Licia Carlson, *The Faces of Intellectual Disability* (Bloomington: Indiana University Press, 2010); and Sophia Isako Wong, "At Home with Down Syndrome and Gender," *Hypatia* 17, no. 3 (2002): 89–117. There is also a critical set of historical texts addressing cognitive impairments through a disability studies lens. See, for example, Martin S. Pernick, *The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures since 1915* (New York: Oxford University Press, 1996); and James W. Trent, Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1995).

36. Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor: University of Michigan Press, 2011); Ellen Samuels, "My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse," *GLQ: A Journal of Lesbian and Gay Studies* 9, nos. 1–2 (2003): 233–55; and Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia: A Journal of Feminist Philosophy* 16, no. 4 (2001): 17–33.

37. Signorello et al. explain that "[r]easons for racial disparities in diabetes prevalence are not clear, but behavioral, environmental, socioeconomic, physiological, and genetic contributors have all been postulated." Their findings suggest that these differences cannot be attributed to "race" per se, but to other established risk factors including socioeconomic status. L. B. Signorello et al., "Comparing Diabetes Prevalence between African Americans and Whites of Similar Socioeconomic Status," *American Journal of Public Health* 97, no. 12 (2007): 2260. For a critique of race-based medicine, see Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century* (New York: The New Press, 2011).

38. Chris Bell, "Introducing White Disability Studies: A Modest Proposal," in *The Disability Studies Reader*, 2nd ed. (New York: Routledge, 2006): 275–82. Nirmla Evevelles and Andrea Minear offer a productive reading of theories of intersectionality through the lens of disability studies; they work in both directions, interrogating the whiteness of disability studies and the inattention to disability in critical race studies. Nirmla Evevelles and Andrea Minear, "Unspeakable Offenses: Untangling Race and Disability in Discourses of Intersectionality," *Journal of Literary and Cultural Disability Studies* 4, no. 2 (2010): 127–45. See also Corbett Joan O'Toole, "The Sexist Inheritance of the Disability Movement," in *Gendering Disability*, ed. Bonnie G. Smith and Beth Hutchison (New Brunswick, NJ: Rutgers University Press, 2004), 294–95.

39. Carrie Sandahl, "Queering the Crip or Crippling the Queer: Intersections of Queer and Crip Identities in Solo Autobiographical Performance," *GLQ* 9, nos. 1–2 (2003): 27; Robert McKuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006), 36.

40. Robert Hoffmeister, "Border Crossings by Hearing Children of Deaf Parents: The Lost History of Codas," in *Open Your Eyes: Deaf Studies Talking*, ed. H.-Dirksen L. Bauman (Minneapolis: University of Minnesota Press, 2008), 189–215; see also Lennard J. Davis, *My Sense of Silence:*

*Memoirs of a Childhood with Deafness* (Champaign: University of Illinois Press, 2000). Brenda Jo Brueggemann offers a productive examination of deaf identity and the space between identities. Brenda Jo Brueggemann, *Deaf Subjects: Between Identities and Places* (New York: New York University Press, 2009).

41. McKuer, *Crip Theory*, 36–37.

42. Linton, *Claiming Disability*, 13. See also Carlson, *Faces of Intellectual Disability*, 192–94.

43. Drawing on her work on disability in Botswana, Julie Livingston suggests the term "debility" as an alternative to disability because it encompasses chronic illness, aging, and a wide range of impairments, not just "disability per se." Livingston, "Insights," 113.

44. Ladelle McWhorter, foreword to *Foucault and the Government of Disability*, ed. Shelley Tre-main (Ann Arbor: University of Michigan Press, 2005), xv.

45. For a discussion of the inclusion of women who do not identify as feminists in feminist political activism and coalition work, see Sohara Syeda and Becky Thompson, "Coalition Politics in Organizing for Mumia Abu-Jamal," in *Feminism and Antiracism: International Struggles for Justice*, ed. France Winddance Twine and Kathleen M. Blee (New York: New York University Press, 2001), 193–219.

46. In some of his recent work on disability and identity politics, Lennard J. Davis provides a progress narrative of theories of identity in which he consigns the work of feminist and queer theorists to earlier, problematic stages, with disability—a disability apparently separate from feminist and queer theory—offering a solution to the problems of identity politics. See *Bending Over Backwards: Disability, Dismodernism, and other Difficult Positions* (New York: New York University Press, 2002), 9–32. For a brief critique of Davis's representation of feminist and queer theory and activism, see McKuer, *Crip Theory*, 202.

My desire to make these links explicit echoes the work of Gayatri Gopinath, who, in her study of queer diasporas, "challenges the notion that these fields of inquiry [queer and feminist scholarship] are necessarily distinct, separate, and incommensurate." Gayatri Gopinath, *Impossible Desires: Queer Diasporas and South Asian Public Cultures* (Durham, NC: Duke University Press, 2005), 16.

47. Nancy Maiz, *Plaintext: Essays* (Tucson: University of Arizona Press, 1992), 9.

48. On the dynamic of staring, see Rosemarie Garland-Thomson, *Staring: How We Look* (New York: Oxford University Press, 2009).

49. Eli Clare, *Exile and Pride: On Disability, Queerness, and Liberation* (Boston: South End Press, 1999), 70.

50. Sandahl, "Queering the Crip," 53n1; McKuer, *Crip Theory*, 35.

51. "Critical disability studies" is another term describing this orientation toward disability and disability studies; as Margrit Shildrick describes it, critical disability studies is the frame favored "by those . . . for whom the original challenge of the social model of disability no longer provides an effectively dynamic model." Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity, and Sexuality* (New York: Palgrave Macmillan, 2009), 15.

52. Sandahl, "Queering the Crip," 27.

53. Part of my reluctance to articulate a strict boundary between feminist disability studies (or queer disability studies) and crip theory stems from an awareness that contradictory strategies and epistemologies often circulate under the same name. Merri Lisa Johnson explains, for example, that some work marked "feminist disability studies" refuses all medical terminology while other feminist disability studies approaches do not; similarly, some "disability studies" texts deconstruct the disabled/nondisabled binary while others reify it. Moreover, I worry about the possibility of "crip theory" being positioned as a successor narrative to disability studies, as if all the problems with the field could be solved with this one shift in approach. (After all, crip theory could also be critiqued, in Bell's terms, as *white crip theory*.) I hasten to add that neither McKuer nor Sandahl have positioned crip theory this way, and both continue to practice and claim "disability studies"; I believe their

distinction invites a contestatory approach to both disability and disability studies while remaining invested in the promises of the field as a whole. For an example of a theorist who is interested in mapping the differences between feminist disability studies and crip feminism, see Merri Lisa Johnson, "Crip Drag Swan Queen: Two Readings of Darren Aronofsky's *Black Swan*," National Women's Studies Association Conference, Atlanta, GA, November, 2011.

54. "Compulsory able-mindedness" is a way of capturing the normalizing practices, assumptions, and exclusions that cannot easily be described as directed (exclusively) to physical functioning or appearance. Kristen Harmon suggests, for example, that "able-bodiedness" cannot sufficiently address what she calls "compulsory hearing." Kristen Harmon, "Deaf Matters: Compulsory Hearing and Ability Trouble," in *Deaf and Disability Studies: Interdisciplinary Perspectives*, ed. Susan Burch and Alison Kaler (Washington, DC: Gallaudet University Press, 2010), 42. For extensive analyses of compulsory able-mindedness in terms of mental disability, see Andrea Nicki, "The Abused Mind: Feminist Theory, Psychiatric Disability, and Trauma," *Hypatia* 16, no. 4 (2001): 80–104; and Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor: University of Michigan Press, 2010).

55. Anna Mollow makes a similar argument in her discussion of depression and mental illness: to engage fully with questions of mental illness, disability studies will need to shift its guiding frameworks and terminologies. Mollow, "When Black Women Start Going on Prozac." See also Elizabeth J. Donaldson, "Revisiting the Corpus of the Madwoman: Further Notes toward a Feminist Disability Studies Theory of Mental Illness," in *Feminist Disability Studies*, ed. Kim Q. Hall (Bloomington: Indiana University Press, 2011), 91–113.

56. Judith Butler, *Bodies That Matter: On the Discursive Limits of "Sex"* (New York: Routledge, 1993), 223.

57. Carrie Sandahl expresses the same hope, and concern, noting that queer theory (and, I would add, disability studies) has a "tendency to absorb and flatten internal differences, in particular to neutralize its constituents' material and cultural differences and to elevate the concerns of gay white men [or middle-class white male wheelchair users] above all others." Sandahl, "Queering the Crip," 27.

58. Matilda suggests that it is in the "messiness" of intersectional work that "the possibility for a rigorous analysis emerges." Jason Ruiz, "The Violence of Assimilation: An Interview with Matilda aka Matt Bernstein Sycamore," *Radical History Review* 100 (Winter 2008): 239.

59. Jasbir K. Puar, *Terrorist Assemblages: Homonationalism in Queer Times* (Durham, NC: Duke University Press, 2007), 212.

60. Of course, this lack is even more pronounced in the other direction: papers on disability studies topics or drawing on disability theory remain few and far between at many cultural studies and critical theory conferences.

61. Puar, *Terrorist Assemblages*, 209; emphasis in original.

62. Janet Price and Margrit Shildrick play with this desire for and practice of disability identification in some of their collaborative work, as do Robert McKuer and Anna Mollow. See Price and Shildrick, "Uncertain Thoughts"; and Mollow and McKuer, introduction to *Sex and Disability*.

63. John B. Kelly's analysis of quad rugby offers a potent reminder that ableism or, in his framing, the ideology of ability, affects relationships between disabled people. John B. Kelly, "It Could Have Been Worse: Quadriplegic Athletes and the Ideology of Ability," Society for Disability Studies Annual Meeting, Chicago, June 2000.

64. Eve Kosofsky Sedgwick, *Tenderness* (Durham, NC: Duke University Press, 1994), xiv. See also Margaret Price, "Her Pronouns Wax and Wane: Psychosocial Disability, Autobiography, and Counter-Diagnosis," *Journal of Literary and Cultural Disability Studies* 3, no. 1 (2009): 11–33.

65. Robert McKuer and Abby L. Wilkerson, "Introduction," *GLQ: A Journal of Lesbian and Gay Studies* 9, nos. 1–2 (2003): 13.

## Chapter 1

1. David Penna and Vickie D'Andrea-Penna, "Developmental Disability," in *Encyclopedia of U.S. Disability History*, ed. Susan Burch (New York: Facts on File, 2009), 261–62.

2. As I noted in the introduction, *disabled* can also be a temporary category. Some people have illnesses or disabilities whose manifestations come and go repeatedly over the course of their lives; others may see their illnesses or disabilities cured, either through medical intervention or "over time." Moreover, the meanings of *disabled* shift significantly by and in context, such that determining a timeless definition is both futile and, I would argue, misguided. As Margrit Shildrick reminds us, part of the work of critical disability studies is to trouble the distinction between disabled and able-bodied, or between disabled and nondisabled. Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity, and Sexuality* (New York: Palgrave Macmillan, 2009); Janet Price and Margrit Shildrick, "Uncertain Thoughts on the Disabled Body," in *Vital Signs: Feminist Reconfigurations of the Biological Body*, ed. Margrit Shildrick and Janet Price (Edinburgh: Edinburgh University Press, 1998), 224–49.

3. In the same volume, Michael Bérubé urges an accounting "of temporality in our theories of identity," including disability. Sharon Snyder, Brenda Brueggemann, and Rosemarie Garland-Thomson, "Introduction: Integrating Disability in Theory and Scholarship," in *Disability Studies: Enabling the Humanities*, ed. Sharon Snyder, Brenda Brueggemann, and Rosemarie Garland-Thomson (New York: Modern Language Association of America, 2002), 2; Michael Bérubé, "Afterword: If I Should Live So Long," in *Disability Studies: Enabling the Humanities*, ed. Sharon Snyder, Brenda Brueggemann, and Rosemarie Garland-Thomson (New York: The Modern Language Association of America, 2002), 339.

4. Donald McNeil, Jr., "Broad Racial Disparities Seen in Americans' Ills," *New York Times*, January 14, 2011. Researchers note similar health disparities between straight people and gays, lesbians, and bisexuals, particularly as they age. Roni Caryn Rabin, "Disparities: Illness More Prevalent among Older Gay Adults," *New York Times*, April 1, 2011.

5. Irving Kenneth Zola, "The Language of Disability: Problems of Politics and Practice," *Australian Disability Review*, 1988, accessed January 6, 2011, <http://www.disabilitymuseum.org/lib/docs/83card.htm>; Carol J. Gill, "A Psychological View of Disability Culture," *DSQ: Disability Studies Quarterly* 15, no. 4 (1995): 16–19.

6. Some readers will recognize similarities to "people of color time" and "queer time."

7. *Dictionary of American Slang*, "crip time," accessed January 6, 2011, <http://www.diclib.com/cgi-bin/di.cgi?base=amslang&page=showid&id=2159>.

8. Kate Bornstein suggests that some trans-identified folks might find themselves with similar temporal needs: "[A] newly transgendered person . . . moves just a bit slower than most people; he or she is unlearning old ways of moving, and picking up new ways of moving. So one of the first things you try to do is to move at a normal pace." Kate Bornstein, *Gender Outlaw: On Men, Women, and the Rest of Us* (New York: Vintage, 1995), 87.

9. Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor: University of Michigan Press, 2011), 62. See also Margaret Price, "Access Imagined: The Construction of Disability in Conference Policy Documents," *DSQ: Disability Studies Quarterly* 29, no. 1 (2009), <http://www.ds-q-sds.org/article/view/174/174>.

10. For examples of queer approaches to temporality, see Judith Halberstam, *In a Queer Time and Place: Transgender Bodies, Subcultural Lives* (New York: New York University Press, 2005); and Elizabeth Freeman, ed., "Queer Temporalities," special issue of *GLQ: A Journal of Gay and Lesbian Studies* 13, nos. 2–3 (2007). Lee Edelman's polemic against the future and José Esteban Muñoz's articulation of a queer futurity can also be seen as part of the larger queer exploration of temporality, as can Elizabeth Freeman's and Heather Love's engagements with queer history and queer



historiography. Lee Edelman, *No Future: Queer Theory and the Death Drive* (Durham, NC: Duke University Press, 2004); José Esteban Muñoz, *Cruising Utopia: The Then and There of Queer Futurity* (New York: New York University Press, 2009); Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham, NC: Duke University Press, 2010); and Heather Love, *Feeling Backward: Loss and the Politics of Queer History* (Cambridge, MA: Harvard University Press, 2009).

The 2009 Society for Disability Studies Conference referred to temporality in its general theme—"It's Our Time: Pathways to and from Disability Studies: Past, Present, Future"—but few of the papers at the conference engaged with queer temporality (or with theories of futurity and temporality in general); similarly, the special issue of *DSQ: Disability Studies Quarterly* that showcased several papers from the conference featured no such engagement with queer approaches to temporality. Jim Ferris, ed., "In (Dis)ability Time," *DSQ: Disability Studies Quarterly* 30, nos. 3–4 (2010).

11. As Carrie Sandahl puts it, "Crippling spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects." In turning my attention to "queer time," I propose expanding the terrain of crippling to include not only "mainstream representations or practices" but also *queer* representations and practices. How do they, too, "reveal able-bodied assumptions and exclusionary effects"? 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, nos. 1–2 (2003): 37.

12. For an incisive queer reading of rehabilitation, see Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006), especially 103–45.

13. Much as an individual's desire for a cure does not necessarily signal an adherence to a curative imaginary but can, instead, be felt alongside a strong crip affiliation, so, too, can these questions exist apart from a curative temporality. Indeed, such questions can be used to animate a crip temporality if they serve to trouble the abled/disabled binary or to disrupt the assumed stability of disability categories and diagnoses. I refer here only to the more common framing of these questions.

14. Carla Freccero, "Fuck the Future," *GLQ: A Journal of Gay and Lesbian Studies* 12, no. 2 (2006): 332–34.

15. Edelman, *No Future*, 11. See also Lauren Berlant, *The Queen of America Goes to Washington City: Essays on Sex and Citizenship* (Durham, NC: Duke University Press, 1997).

16. *Ibid.*, 11, 3.

17. *Ibid.*, 3.

18. Patrick McCreery, "Save Our Children/Let Us Marry: Gay Activists Appropriates the Rhetoric of Child Protectionism," *Radical History Review* 2008, no. 100 (2008): 186–207.

19. Testing "positive" is not a guarantee that a child will have a certain disability, and most tests are unable to determine the extent of a child's impairment; children with Down syndrome, for example, differ widely in their level of function. For extended analyses of prenatal testing practices, see Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999); and Janelle S. Taylor, *The Public Life of the Fetal Sonogram: Technology, Consumption, and the Politics of Reproduction* (New Brunswick, NJ: Rutgers University Press, 2008).

20. Edelman, *No Future*, 30.

21. Shannon Winnubst, "Temporality in Queer Theory and Continental Philosophy," *Philosophy Compass* 5, no. 2 (2010): 138.

22. The only "cure" available for most conditions detected by prenatal testing is selective abortion; there have been recent breakthroughs in fetal surgery, but those are still preliminary and only work for certain conditions. See Pam Belluck, "Success of Spina Bifida Study Opens Fetal Surgery Door," *New York Times*, February 9, 2011, A1.

23. *Buck v. Bell*, 274 U.S. 200, 1927, accessed September 13, 2010, <http://laws.findlaw.com/us/274/200.html>. See also Paul Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* (Baltimore, MD: The Johns Hopkins University Press, 2008).

24. For histories of eugenics in the United States, see, among others, Susan Burch and Hannah Joyner, *Unspeaking: The Story of Junius Wilson* (Chapel Hill: University of North Carolina Press, 2007); Wendy Kline, *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom* (Berkeley: University of California Press, 2001); Nancy Ordover, *American Eugenics: Race, Queer Anatomy, and the Science of Nationalism* (Minneapolis: University of Minnesota Press, 2003); Martin S. Pernick, *The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures since 1915* (New York: Oxford University Press, 1996); Michael A. Rembis, *Defining Deviance: Sex, Science, and Delinquent Girls, 1890–1960* (Champaign: University of Illinois Press, 2011); Johanna Schoen, *Choice and Coercion: Birth Control, Sterilization, and Abortion in Public Health and Welfare* (Chapel Hill: University of North Carolina Press, 2005); Steven Selden, *Inheriting Shame: The Story of Eugenics and Racism in America* (New York: Teachers College Press, 1999); and James Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1994).

25. See, for example, Elena R. Gutiérrez, *Fertile Matters: The Politics of Mexican-Origin Women's Reproduction* (Austin: University of Texas Press, 2008); Jennifer Nelson, *Women of Color and the Reproductive Rights Movement* (New York: New York University Press, 2003); and Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage, 1999).

26. For more on institutionalization and the need for community-based care, see Laura Hershey, *Just Help* (unpublished manuscript), 271–72; Harriet MacBryde Johnson, "The Disability Gulag," *New York Times Magazine*, November 23, 2003, <http://www.nytimes.com/2003/11/23/magazine/the-disability-gulag.html>; and Jennifer LaFleur, "Nursing Homes Get Old for Many with Disabilities," *ProPublica*, June 21, 2009, <http://www.propublica.org/article/nursing-homes-get-old-for-many-with-disabilities-621>.

27. Mary Storer Kostir, "The Family of Sam Sixty," in *White Trash: The Eugenic Family Studies, 1877–1919*, ed. Nicole Hahn Rafter (Boston: Northeastern University Press, 1988), 208, emphasis in original.

28. The full passage reads: "A community can follow one of three courses in dealing with the problem of parenthood among its mentally diseased and mentally deficient members who are not able to control their own fecundity. 1. It may do nothing at all. That is what most communities are now doing. The results are not satisfactory either to the community or to the patients. They are disastrous in their effect in future generations. 2. It may keep such patients under lock and key for the rest of their lives, or at least for the rest of their reproductive lives. Such a policy is too expensive to reach more than a minority, and is therefore impracticable. Even if possible, it would in many cases be an unnecessary hardship or cruelty to the patient. 3. It may use sterilization in selected cases, as an adjunct to a careful system of parole and supervision, which will aid patients to live in the community, to be self-supporting, and at the same time not put a new burden on society or pass on their handicaps to posterity."

Eugenic sterilization is no panacea, but it is one of the many tested and dependable measures that will help reduce the burdens and increase the happiness and prosperity of the population in this and future generations. As such, it is one among many indispensable procedures in any modern program of social welfare." *Human Sterilization* (Pasadena, CA: Human Betterment Foundation, 1933), 6; Cold Spring Harbor Eugenics Archive, accessed September 13, 2010, <http://tinyurl.com/8gcrudb>.

29. For examples of this critique of Edelman, see Muñoz, *Cruising Utopia*; and Jasbir K. Puar, *Territorial Assemblages: Homonationalism in Queer Times* (Durham, NC: Duke University Press, 2007). Shannon Winnubst shares with Edelman a suspicion of the future, and both are wary of political talk of utility or social value. But Winnubst departs from Edelman in her recognition that many people have never had the cultural or economic capital to project themselves into the future in the first place; like Muñoz and Puar, she is concerned with the role of whiteness in the reproductive imaginary. Shannon Winnubst, *Queering Freedom* (Bloomington: Indiana University Press, 2006).

30. Edelman, *No Future*, 11, 29.
31. Heather Love, "Wedding Crashers," *GLQ: A Journal of Lesbian and Gay Studies* 13, no. 1 (2007): 131.
32. Muñoz, *Cruising Utopia*, 95.
33. Sarah Horton and Judith C. Barker, "'Stains' on Their Self-Discipline: Public Health, Hygiene, and the Disciplining of Undocumented Immigrant Parents in the Nation's Borderlands," *American Ethnologist* 36, no. 4 (2009): 785.
34. Susan Schwelk similarly describes how categories of health and hygiene were used "as a means of white frashing, in which poor whiteness or bad whiteness (filthy, debilitated, dangerous, debris) sets off the nice body of good whiteness." Susan M. Schwelk, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2009), 185; and Anna Stubbs, "Beyond the Pale: Tainted Whiteness, Cognitive Disability, and Eugenic Sterilization," *Hypatia* 22, no. 2 (2007): 162, 163. For more on historical links between whiteness and (racial) hygiene, see, for example, Mel Y. Chen, *Animacies: Biopolitics, Racial Mattering, and Queer Affect* (Durham, NC: Duke University Press, forthcoming); Natalia Molina, "Constructing Mexicans as Deportable Immigrants: Race, Disease, and the Meaning of 'Public Charge,'" *Identities: Global Studies in Culture and Power* 17 (2010): 641–66; Natalia Molina, "Medicalizing the Mexican: Immigration, Race, and Disability in the Early-Twentieth-Century United States," *Radical History Review* 94 (2006): 22–37; and Nayan Shah, *Contagious Divides: Epidemics and Race in San Francisco's Chinatown* (Berkeley: University of California Press, 2001).
35. Horton and Barker, "Stains on Their Self-Discipline," 796.
36. Quoted in Cathy Cohen, "Punks, Bullfighters, and Welfare Queens: The Radical Potential of Queer Politics?" in *Black Queer Studies: A Critical Anthology*, ed. E. Patrick Johnson and Mae G. Henderson (Durham, NC: Duke University Press, 2009), 40. Cohen offers a concise and incisive critique of Moynihan's project; see also Mattie Udora Richardson, "No More Secrets, No More Lies: African-American History and Compulsory Heterosexuality," *Journal of Women's History* 15, no. 3 (2003): 63–76; and Hortense Spillers, "Mama's Baby, Papa's Maybe: An American Grammar Book," *Diacritics* 17, no. 2 (1987): 64–81.
37. Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century* (New York: The New Press, 2011), 94. See also Erevellas, *Disability and Difference in Global Contexts*; and Beth A. Ferri and David O'Connor, *Reading Resistance: Discourses of Exclusion in Desegregation and Exclusion Debates* (New York: Peter Lang, 2006).
38. I read McRuer's entire *Crip Theory* as a sustained argument to this effect; indeed, to do crip theory is to recognize and refuse this call to normalization in all its guises.
39. Puar, *Territorial Assemblages*, 211.
40. Noam Ostrander, "When Identities Collide: Masculinity, Disability, and Race," *Disability and Society* 23, no. 6 (2008): 594.
41. Kevin Sack, "Research Finds Wide Disparities in Health Care by Race and Region," *New York Times*, June 5, 2008, <http://www.nytimes.com/2008/06/05/health/research/osdisparities.html>; see also Roberts, *Fatal Invention*, 102.
42. As Ed Cohen and Julie Livingston explain, "Inequality does not name a natural imbalance; it bespeaks systematic and relentless devaluations. And, as with all instances of (d)evaluation, the hierarchies it inscribes result from decisions." Asking these kinds of questions—of incidence and occurrence—reminds us that decisions can be made differently. Ed Cohen and Julie Livingston, "AIDS," *Social Text* 27, no. 3 (2009): 40.
43. Elizabeth Freeman, introduction to "Queer Temporalities," special issue of *GLQ: A Journal of Gay and Lesbian Studies*, 13 nos. 2–3 (2007): 159, emphasis in the original.
44. *Ibid.*, 160.
45. Ellen Samuels makes this argument about Halberstam, tracing her unmarked relationship to disability studies. Ellen Samuels, "Normative Time: How Queerness, Disability, and Parenthood

Impact Academic Labor," paper presented at the Modern Languages Association Annual Meeting, December 2006.

46. Freeman, introduction, 159.
47. Halberstam, *In a Queer Time and Place*, 1.
48. *Ibid.*, 152.
49. *Ibid.*, 153.
50. *Ibid.*, 2.
51. *Ibid.*, 1.
52. *Ibid.*, 2.
53. *Ibid.*, 2.
54. Robert McRuer has long argued for a more robust and critical investment in the relationships among AIDS theory, queer theory, and disability studies. While such links might already be implicit in some disability and AIDS activism and scholarship, McRuer urges us to make them explicit, "continually focusing on a queer/disabled collectivity, surrounding AIDS theorists with a larger disability community and vice versa." Building on his insights, I think part of this work includes remembering that the time of the epidemic is not over. See Robert McRuer, "Critical Investments: AIDS, Christopher Reeve, and Queer/Disability Studies," *Journal of Medical Humanities* 23, nos. 3–4 (2002): 226.
55. Tom Boellstorff, "When Marriage Fails: Queer Coincidences in Straight Time," *GLQ* 13, nos. 2–3 (2007): 228.
56. Eliza Chandler, "Sidewalk Stories: The Troubling Task of Identification," *Disability Studies Quarterly* 30, nos. 3–4 (2010), <http://www.ds-qds.org/article/view/1293/1329>.
57. Jain mentions in passing that prognosis time might be a way to rethink disability beyond identity politics—for don't we all live under prognosis to some degree?—a claim that Puar then takes up in her own ruminations on prognosis time. I share their interest in thinking disability beyond disabled bodies; indeed, part of my fascination with crip temporalities is how thinking through time might push us all to consider disability differently. Sarah Loichann Jain, "Living in Prognosis: Toward an Elegiac Politics," *Representations* 98 (Spring 2007): 80–81; Jasbir K. Puar, "Prognosis Time: Toward a Geopolitics of Affect, Debility and Capacity," *Women and Performance: A Journal of Feminist Theory* 19, no. 2 (2009): 161–72.
58. Laura Hershey, *Just Help*, 168.
59. Jain discusses these kinds of negotiations as a reckoning with both fantasies of the future and counterfactual futures and pasts. Jain, "Living in Prognosis."
60. Cynthia Daniels discusses the difficulties veterans face in persuading the government to acknowledge the effects of Agent Orange and Iraq War Syndrome on men's reproductive health. *Exposing Men: The Science and Politics of Male Reproduction* (New York: Oxford University Press, 2006).

61. Carolyn Dinshaw et al., "Theorizing Queer Temporalities: A Roundtable Discussion," *GLQ: A Journal of Gay and Lesbian Studies* 13, nos. 2–3 (2007): 192.

62. Nealon asks this question in terms of working-class gay men and gay men of color returning again and again to gay bars where they feel—are made to feel—unwelcome. I deploy it here not only to ask these questions of diagnosis/undiagnosis/misdiagnosis but also out of a recognition that these questions are similarly bound up in questions of race and class. How have popular representations of MCS and chronic fatigue as illnesses (or, often, "illnesses") striking the white and upper/middle class made it impossible to see MCS in populations of color? Or, to put it differently, how have populations of color been seen as always already polluted and therefore exceeding diagnoses of MCS? Moving to other diagnostic categories, how have labels of "learning disability" and "behavioral/emotional disability" been attached to different populations differently, with white students more likely to fit the former classification and students of color the latter? Or, more broadly, how are students of color overrepresented in special education classrooms? For more on these questions, see Chen, *Animacies*;



Nirmala Erevelles and Andrea Minear, "Unspeakable Offenses: Untangling Race and Disability in Discourses of Intersectionality," *Journal of Literary and Cultural Disability Studies* 4, no. 2 (2010): 127–45; and Ferri and O'Connor, *Reading Resistance*.

63. Rhonda Zwilling, *The Dispossessed: Living with Multiple Chemical Sensitivities* (Paulden, AZ: The Dispossessed Outreach Project, 1999), 61. See also Stacy Alaimo, *Bodily Natures: Science, Environment, and the Material Self* (Bloomington: Indiana University Press, 2010).

64. Mel Y. Chen, "Toxic Animacies, Inanimate Affectations," *GLQ: A Journal of Lesbian and Gay Studies* 17, nos. 2–3 (2011): 274.

65. Chen, "Toxic Animacies," 277.

66. *Ibid.*, 274–78. Peggy Munson similarly describes feeling alienated, or even violated, by the bodies of those around her. She reads erotic possibility into going scent-free, describing it as a kind of radical femme surrender. Peggy Munson, "Fringe Dweller: Toward an Ecofeminist Politics of Femme," in *Visible: A Feministology*, vol. 2, ed. Jennifer Clarke Burke (Ypsilanti, MI: Homolactis Press, 2009), 28–36.

67. Anna Mollow suggests that this "unknowingness" is limited. We may not know, understand, or believe that our use of fragrance- or chemical-laden products makes others ill, but we do expect—and want—our use of fragrances to be apparent to others. As she explains, "the phrase 'personal care products' is something of a misnomer: the fragrances these products contain are designed to affect many others besides those who choose to apply them. People don't pay forty-five dollars for a bottle of Calvin Klein's Eternity so that they can sit alone in their living rooms and inhale its forty-one chemical ingredients (several of which the EPA and other governmental agencies list as toxic). Rather, they expect that these ingredients will permeate the air and enter the bodies of everyone who comes in contact with them." Anna Mollow, "No Safe Place," *WSQ: Women's Studies Quarterly* 39, nos. 1–2 (2011): 194–95.

68. Johnson, "Disability Gating."

69. For a personal description of such accounting, see Christine Misserandino, "The Spoon Theory," 2003, <http://www.butyoudontlookstuck.com>.

70. Halberstam's book was written before the economic downturn, when "unemployed" was more likely to refer to those considered "unemployable" or those unemployed by choice rather than the massive groups of unemployed people now. Halberstam, *In a Queer Time and Place*, 10.

71. Samuels, "Normative Time," 5.

72. Catherine Kudlick notes that much of the language we use in the academy to evaluate ourselves and our colleagues—measuring up, pulling our own weight—bear the marks of industrial capitalism's focus on fitness and punctuality. Catherine Kudlick, "A History Profession for Every Body," *Journal of Women's History* 18, no. 1 (2006): 163–64. See also Price, *Mad at School*.

73. Halberstam, *In a Queer Time and Place*, 4.

74. *Ibid.*, 4, 152.

75. *Ibid.*, 2.

76. McKuer, *Crip Theory*, 183.

77. Halberstam, *In a Queer Time and Place*, 4.

78. *Ibid.*, 3.

79. *Ibid.*, 3.

80. Winnubst, *Queering Freedom*, 186.

81. Georgina Kleege, *Blind Rage: Letters to Helen Keller* (Washington, DC: Gallaudet University Press, 2006); and Brenda Jo Brueggemann, *Deaf Subjects: Between Identities and Places* (New York: New York University Press, 2009).

82. As Elizabeth Freeman suggests, "[W]riting is a way to speak with the dead, reanimate the past, gamble that there was one at all." Freeman, introduction, 168.

83. Muñoz, *Cruising Utopia*, 37.

84. Le'a Kent, "Fighting Abjection: Representing Fat Women," in *Bodies Out of Bounds: Fatness and Transgression*, ed. Jana Evans Braziel and Kathleen LeBesco (Berkeley: University of California Press, 2001), 135.

85. Elena Levy-Navarro, "Fattening Queer History: Where Does Fat History Go from Here?" in *The Fat Studies Reader*, ed. Esther Rothblum and Sondra Solovay (New York: New York University Press, 2009), 18.

86. Some writers are interested in a cure, some are not, and many are ambivalent, but all feel the need to address the issue in one form or another. See, among others, Eli Clare, *Exile and Pride: Disability, Queerness, and Liberation* (Boston: South End Press, 1999); Nancy Mairs, *Wais-High in the World: A Life among the Nondisabled* (Boston: Beacon Press, 1996); Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996); and Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia: A Journal of Feminist Philosophy* 16, no. 4 (2001): 17–33.

87. Wendell, *Rejected Body*, 83.

88. Clare, *Exile and Pride*, 106.

89. Catherine Scott, "Time Out of Joint: The Narcotic Effect of Prolepsis in Christopher Reeve's *Still Me*," *Biography* 29, no. 2 (2006): 309.

90. Halberstam, *In a Queer Time and Place*, 3.

91. Liat Ben-Moshe, Jean Stewart, and Maria Russell have argued for a disability rights movement that recognizes the overlaps between disability and the prison-industrial complex. Liat Ben-Moshe, "Disabling Incarceration: Connecting Disability to Divergent Confinements in the USA," *Critical Sociology* (2011): 1–19; and Jean Stewart and Maria Russell, "Disablement, Prison, and Historical Segregation," *Monthly Review* 53, no. 3 (2001): 61–75.

92. For a powerful reflection and analysis of one example of such effects, see Hiram Perez, "You Can Have My Brown Body and Eat It, Too!" *Social Text* 84–85, vol. 23, nos. 3–4 (2005): 171–91.

93. For the concept of the "lust of recognition," see Mia Mingus, Leeh Lakshmi Piepza-Samarinsha, and Ellyer Russian, "Crip Sex: Crip Lust, and the Lust of Recognition," *Leaving Evidence*, May 25, 2010, <http://leavingevidence.wordpress.com/2010/05/25/video-crip-sex-crip-lust-and-the-lust-of-recognition/>.

94. Robert McKuer and Abby Wilkerson coedited an issue of *GLQ* around this question of "desiring disability." They explain, "[W]e both present this special issue and offer it as part of the project of producing spaces in which desiring disability is not simply tolerated or incorporated into already constituted (able-bodied) spaces (including that of queer theory as it has generally been shaped)." Robert McKuer and Abby L. Wilkerson, introduction to "Desiring Disability: Queer Theory Meets Disability Studies," special issue of *GLQ* 9, nos. 1–2 (2003): 13.

95. Sedgwick, *Tendencies*, 161, emphasis in original. Le'a Kent makes a similar point about fat bodies, particularly fat female bodies. What we need, she argues, is a manual showing that "it might be possible to live as a fat woman." Kent, "Fighting Abjection," 132, emphasis in original.

96. Sedgwick, *Tendencies*, 184.

97. Love, *Feeling Backward*, 26.

98. Judith Butler, *Undoing Gender* (New York: Routledge, 2004), 29.

99. Stacey Milbern (Cripchick) urges queer and disability communities to think through how conceptions of "coming out," "out," and "visibility" are marked by privilege. Too often, she laments, coming out requires leaving one's community. Ellen Samuels raises additional questions about the logic of visibility and its presumed relationship to pride. Cripchick, "Thoughts on National Coming Out Day," October 11, 2010, <http://blog.cripchick.com/archives/8359>; Ellen Samuels, "Bodies in Trouble," in *Restricted Access: Lesbians on Disability*, ed. Victoria A. Brownworth (Seattle: Seal Press, 1999), 192–200.

100. Chandra Talpade Mohanty and Biddy Martin offer insight into the trope of “home” in feminist theory, and in so doing they craft a lineage including both Minnie Bruce Pratt and Bernice Johnson Reagon. Chandra Talpade Mohanty and Biddy Martin, “What’s Home Got to Do with It?” in *Feminism Without Borders: Decolonizing Theory, Practicing Solidarity* (Dunham, NC: Duke University Press, 2003), 86–105; see also Minnie Bruce Pratt, *Rebellion: Essays, 1980–1991* (Ann Arbor, MI: Firebrand, 1991); and Bernice Johnson Reagon, “Coalition Politics: Turning the Century,” in *Home Girls: A Black Feminist Anthology*, ed. Barbara Smith (New York: Kitchen Table Press, 1983), 356–68.

## Chapter 2

1. D. F. Gunther and D. S. Diekema, “Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma,” *Archives of Pediatrics and Adolescent Medicine* 160, no. 10 (2006): 1014.

2. *Ibid.*, 1014.

3. *Ibid.*

4. Following Laura Hershey, I capitalize “treatment” to distinguish between the specific set of surgical and medical interventions used on Ashley (what her parents term “the Ashley Treatment”) and the more abstract, general notion of “treatment” as any set of practices that attempt to solve a problem. As Hershey explains, referring to the interventions as a “treatment” accepts and perpetuates the notion that Ashley’s body was sick or wrong and in need of a cure. Laura Hershey, “Stunting Ashley,” *off our backs* 37, no. 1 (2007): 8.

5. Gunther and Diekema, “Attenuating Growth in Children,” 1014.

6. Although bloggers, journalists, and disability rights activists have tended to examine the Treatment as a whole—addressing growth attenuation, breast bud removal, and hysterectomy all at once—some of the medical and bioethics texts have separated these procedures, focusing on either the growth attenuation or the sterilization. See, for example, John Lantos, “It’s Not the Growth Attenuation, It’s the Sterilization!” *American Journal of Bioethics* 10, no. 1 (2010): 45–46; and Benjamin S. Wilfond, Paul Steven Miller, Carolyn Korfatis, Douglas S. Diekema, Denise M. Dudzinski, Sara Goering, and the Seattle Growth Attenuation and Ethics Working Group, “Navigating Growth Attenuation in Children with Profound Disabilities: Children’s Interests, Family Decision-Making, and Community Concerns,” *Hastings Center Report* 40, no. 6 (2010): 27–40.

7. Lennard Davis describes disability as “a disruption in the visual, auditory, or perceptual field as it relates to the power of the gaze.” As we will see, one of the lines of defense for the Treatment was that it would make it easier for people to see and interact with Ashley; the Treatment would alleviate the alleged visual asynchrony of Ashley’s mind and body. Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York: Verso, 1995), 129.

8. Gunther was Ashley’s endocrinologist; along with Dr. Douglas Diekema, he is one of the doctors most closely identified with the Ashley Treatment. Gunther committed suicide in September 2007, several months after an investigative report determined that the hospital had acted improperly in sterilizing Ashley. In the years since Gunther’s death, Diekema has continued to write about the case, often with Dr. Norman Post.

9. Gunther and Diekema, “Attenuating Growth in Children,” 1013.

10. Ashley’s Mom and Dad, *The “Ashley Treatment”: Towards a Better Quality of Life for “Pillow Angels,”* March 25, 2007 <http://pillowangel.org/Ashley%20Treatment%2007.pdf>; Wilfond et al., “Navigating Growth Attenuation in Children,” 27.

11. The effect of the Treatment on Ashley’s growth, however, is a matter of some debate. Gunther and Diekema explain that the Treatment had to be started quickly because Ashley had already begun to show signs of a growth spurt; what they do not mention is how much of her final height she had

already achieved by the time the estrogen regimen began. As Rebecca Clarren reports, there is a possibility that Ashley was already approaching her maximum size; perhaps the Treatment had only a small effect. Rebecca Clarren, “Behind the Pillow Angel,” *Salon*, February 9, 2007, [http://www.salon.com/news/feature/2007/02/09/pillow\\_angel/index.html](http://www.salon.com/news/feature/2007/02/09/pillow_angel/index.html).

12. As described in the investigative report, “The Washington Protection and Advocacy System (WPAS) is the federally mandated protection and advocacy (P&A) agency for the state of Washington. The P&As, which exist in every state and territory, are ‘watchdog’ agencies with legal authority to under federal statutes to investigate allegations of abuse and neglect of persons with disabilities and to advocate for their legal and human rights.” WPAS changed its name to Disability Rights Washington in 2007 and is part of the National Disability Rights Network. Washington Protection and Advocacy System, “Executive Summary—Investigative Report Regarding the ‘Ashley Treatment,’” *Disability Rights Washington*, 1, last modified October 1, 2010, [http://www.disabilityrightswa.org/home/Executive\\_Summary\\_InvestigativeReportRegardingtheAshleyTreatment.pdf?view=searchterm=ashley](http://www.disabilityrightswa.org/home/Executive_Summary_InvestigativeReportRegardingtheAshleyTreatment.pdf?view=searchterm=ashley). See also <http://www.disabilityrightswa.org/>.

13. Washington Protection and Advocacy System, “Executive Summary,” 1.

14. The committee did, however, sign off on the other two pieces of the Ashley Treatment, the mastectomy and the growth attenuation regimen: “[I]t was the consensus of the Committee members that the potential long term benefit to Ashley herself outweighed the risks; and that the procedures/interventions would improve her quality of life, facilitate home care, and avoid institutionalization in the foreseeable future.” As Clarren notes in her coverage of the case, there were deep divisions in the committee and at the hospital; many at Children’s felt uncomfortable with the team’s decisions. Washington Protection and Advocacy System, Exhibit L, “Special CHRM Ethics Committee Meeting/Consultation,” *Investigative Report Regarding the ‘Ashley Treatment,’* May 4, 2004, [http://www.disabilityrightswa.org/home/Exhibits\\_K\\_T\\_InvestigativeReportRegardingtheAshleyTreatment.pdf](http://www.disabilityrightswa.org/home/Exhibits_K_T_InvestigativeReportRegardingtheAshleyTreatment.pdf); i; Clarren, “Behind the Pillow Angel.”

15. Washington Protection and Advocacy System, Exhibit O, “Letter from Larry Jones,” *Investigative Report Regarding the ‘Ashley Treatment,’* June 10, 2004, [http://www.disabilityrightswa.org/home/Exhibits\\_K\\_T\\_InvestigativeReportRegardingtheAshleyTreatment.pdf](http://www.disabilityrightswa.org/home/Exhibits_K_T_InvestigativeReportRegardingtheAshleyTreatment.pdf), 1.

16. Washington Protection and Advocacy System, “Letter from Larry Jones,” 4.

17. *Ibid.*

18. David Carlson and Deborah Dorfman, “Full Report—Investigative Report Regarding the ‘Ashley Treatment,’” Washington Protection and Advocacy System, May 8, 2007, [http://www.disabilityrightswa.org/home/Full\\_Report\\_InvestigativeReportRegardingtheAshleyTreatment.pdf](http://www.disabilityrightswa.org/home/Full_Report_InvestigativeReportRegardingtheAshleyTreatment.pdf), 14.

19. Carlson and Dorfman, “Full Report,” 14.

20. Washington Protection and Advocacy System, Exhibit T, “Agreement Between Children’s Hospital and Regional Medical Center and the Washington Protection and Advocacy System (Disability Rights Washington) Promoting Protection of Individuals with Developmental Disabilities,” *Investigative Report Regarding the ‘Ashley Treatment,’* May 1, 2007, [http://www.disabilityrightswa.org/home/Exhibits\\_K\\_T\\_InvestigativeReportRegardingtheAshleyTreatment.pdf](http://www.disabilityrightswa.org/home/Exhibits_K_T_InvestigativeReportRegardingtheAshleyTreatment.pdf), 1–2.

21. Jessica Marshall, “Hysterectomy on Disabled US Girl Was Illegal,” *New Scientist*, May 9, 2007, <http://www.newscientist.com/article/dm1809-hysterectomy-on-disabled-us-girl-was-illegal.html>.

22. Wilfond et al., “Navigating Growth Attenuation in Children.”

23. The report does not define “communicative” or “ambulatory”; according to *Dorland’s Illustrated Medical Dictionary*, “ambulatory” refers to someone “able to walk” (*Dorland’s* offers no definition for “communicative”). *Dorland’s Illustrated Medical Dictionary* (Philadelphia: W. B. Saunders Company, 1994), 54; Wilfond et al., “Navigating Growth Attenuation in Children,” 29, 39.

24. Although he supported the group’s decision, Norman Post asserts that “too much deference has been given to the claims of third parties” in medical decision making. He disagrees with the