

1

IDEOLOGY OF CURE

This page intentionally left blank

Birth

I am alive today because of medical technology. Otherwise my mother and I would have been dead long before my first breath, dead as the ovarian cyst that grew beside me. It was as big as a grapefruit before the doctors told her it had to be removed. Her grief, guilt, bitterness twined through that crisis called my birth. She was the first who wanted a cure for the havoc wreaked when the doctors pulled that cyst away. Did I experience it as twin, competitor, invader? Did we wrestle, embrace, vie for space?

They stole her ovary, and a week later I was born. If my father could have held me, I would have fit in one palm, nestled between fingertip and wrist, no bigger than a grapefruit myself, brain cells already dead and misfiring.

Anesthetic, IV, scalpels, sutures saved my mother and me, as did the surgeon who carefully lifted her right ovary out of her abdomen, leaving enough room for me to be born. And in turn, antibiotics, heat lamps, and an incubator kept me alive. I tell this story not as a tragedy, but a truth, a shrug of the shoulders, water over rock. Tell it neither grateful for that crisis nor bitter about the doctors who didn't inform my mother about the cyst growing inside her. They knew about it for years before my conception. Maybe I have them to thank for my birth, the luck of one sperm, one egg. My parents weren't salmon, thrashing a nest into gravel, laying eggs, flooding the water with spawn. But nonetheless, one egg, one sperm—conception is that fragile, that random.

At first all that mattered was her life and mine, but soon she started wishing for a cure, maybe even before she held me, skin to skin.

Prayers, Crystals, Vitamins

Strangers offer me Christian prayers or crystals and vitamins, always with the same intent—to touch me, fix me, mend my cerebral palsy, if only I will comply. They cry over me, wrap their arms around my shoulders, kiss my cheek. After five decades of these kinds of interactions, I still don't know how to rebuff their pity, how to tell them the simple

truth that I'm not broken. Even if there were a cure for brain cells that died at birth, I'd refuse. I have no idea who I'd be without my trembling and tense muscles, slurring tongue. They assume me unnatural, want to make me normal, take for granted the need and desire for cure.

Strangers ask me, "What's your defect?" To them, my body-mind just doesn't work right, defect being a variation of broken, supposedly neutral. But think of the things called defective—the MP3 player that won't turn on, the car that never ran reliably. They end up in the bottom drawer, dumpster, scrapyard. Defects are disposable and abnormal, body-minds or objects to eradicate.

Strangers pat me on the head. They whisper platitudes in my ear, clichés about courage and inspiration. They enthuse about how remarkable I am. They declare me special. Not long ago, a white woman, wearing dream-catcher earrings and a fringed leather tunic with a medicine wheel painted on its back, grabbed me in a bear hug. She told me that I, like all people who tremor, was a natural shaman. Yes, a shaman! In that split second, racism and ableism tumbled into each other yet again, the entitlement that leads white people to co-opt Indigenous spiritualities tangling into the ableist stereotypes that bestow disabled people with spiritual qualities. She whispered in my ear that if I were trained, I could become a great healer, directing me never to forget my specialness. Oh, how *special* disabled people are: we have *special* education, *special* needs, *special* spiritual abilities. That word drips condescension. It's no better than being defective.

Strangers, neighbors, and bullies have long called me *retard*. It doesn't happen so often now. Still, there's a guy down the road who, when he's drunk, taunts me as I walk by with my dog. But when I was a child, *retard* was a daily occurrence. Once, on a camping trip with my family, I joined a whole crowd of kids playing tag in and around the picnic shelter. A slow, clumsy nine-year-old, I quickly became "it." I chased and chased but caught no one. The game turned. Kids came close, ducked away, yelling *retard*. Frustrated, I yelled back for a while. *Retard* became *monkey*. My playmates circled me. Their words became a torrent. "You're a monkey. Monkey. Monkey." I gulped. I choked. I sobbed. Frustration, shame, humiliation swallowed me. My body-mind crumpled. It lasted two minutes or two hours—I don't know. When my father appeared, the circle scattered. Even as the word *monkey* connected me to the nonhuman natural world, I became supremely unnatural.

All these kids, adults, strangers join a legacy of naming disabled people not quite human. They approach me with prayers and vitamins, taunts and endless questions, convinced that I'm broken, special, an inspiration, a tragedy in need of cure, disposable—the momentum of centuries behind them. They have left me with sorrow, shame, and self-loathing.

Beliefs about Disability

Most nondisabled people believe that I need to be repaired. But in another time and place, they might have believed something different. Over the centuries in white Western culture, people now known as disabled have been monsters, gods, goddesses, and oracles. We have been proof of events that happened during our mothers' pregnancies, demonstrations of sin, and markers of evil. We have been evolutionary missing links, charity's favorite objects, the proving ground for Christian miracles. We have been the wild and exotic grist of freak shows, test subjects for the Nazis as they built and refined their gas chambers. We are burdens on society, useless eaters. We are tragedy and heroism. We are out-of-control, excessive, incapable. We are courage, metaphor, cautionary tale, downfall. We are better off dead. Some of these beliefs are long gone; others, still current. They migrate through the centuries, contradicting and bolstering each other.

Some days this history weighs my body-mind down. Depending on the time and place, priests, scientists, freak show managers, philosophers, charity workers, and doctors have all claimed to be the reigning experts on disability. Priests used to cast both disabled people and cure as the will of God. Scientists, naturalists, and anthropologists, responding to the theory of evolution, used to believe that disabled white people and people of color, both disabled and nondisabled, were the missing links between humans and primates. Freak show owners and managers used to make big profits by displaying those same groups of people as wondrous, savage, curious.

Philosophers and pundits have long blamed mothers for their disabled children. Two and three hundred years ago, according to conventional wisdom, a pregnant woman who saw an elephant might give birth to a child who had lumpy skin and enlarged limbs. Today when HIV-positive women, drug users, poor women surviving on welfare become

pregnant, their choices are scrutinized and called immoral, particularly if their babies are born disabled. Sometimes these women are arrested, prosecuted, thrown in jail. Disabled or deaf parents-to-be who might pass on their congenital disabilities commonly face a barrage of criticism. When the deaf lesbian couple Sharon Duchesneau and Candace McCullough sought out a deaf man as a sperm donor so that their child would have a better chance of being deaf, the judgments flew. They were accused of being selfish and unfair to their unborn child. Over the centuries, deaf and disabled people have so often been considered immoral or the markers of immorality.

Charity has long organized itself around the twin notions that disability is tragic and disabled people pitiful. We've become money-makers for Goodwill, the Salvation Army, the Muscular Dystrophy Association, Easter Seals, the Multiple Sclerosis Foundation, Autism Speaks, and on and on. In return they offer us sheltered employment for subminimum wages—sometimes as low as twenty-five cents an hour—and the promise of cure coming our way soon.

My joints ache in this cacophony of belief. For now, doctors inside the medical-industrial complex are the reigning experts, framing disability as a medical problem lodged in individual body-minds, which need to be treated or cured.

Overcoming Disability

Overcoming bombards disabled people. It's everywhere. I think of Whoopi Goldberg. In airports and along freeways, I see her plastered on a billboard sponsored by the Foundation for a Better Life (FBL).¹ Head in hands, dreadlocks threaded through fingers, she furrows her forehead in frustration. Or is it bemusement? She casts her eyes up, looking directly at her viewers. The tagline reads, "Overcame dyslexia," coyly misspelling *overcame*. Underneath those two words brimming with stereotypes sits a red box containing the phrase "HARD WORK," and below that, the command "Pass It On."

The billboard makes me incredulous. The FBL tries to sell a pair of ideas: that Whoopi Goldberg—famous actor, hilarious comedian, Black woman—overcame learning disability through hard work, which, in turn, is a value we need to pass along. That disabled people can only

succeed by overcoming disability is an ableist cliché, but let me turn it inside out. Maybe Goldberg became an actor exactly *because* of her dyslexia. Maybe she developed her kickass humor as a survival strategy to navigate the world as a Black, poor, disabled girl. Maybe she wouldn't have made it big without having a learning disability.

To portray dyslexia as a reversal of *m* and *e* in the word *overcame* is dismissive and stereotypical. To pose individual hard work, rather than broad-based disability access, as the key to success for people with dyslexia is absurd and ableist. To pair a Black woman with the value of hard work in a country that both names Black women as welfare queens and has, for centuries, exploited their back-breaking labor as maids and nannies, factory workers and field hands is demeaning and racist. Actually, the billboard enrages me.

.....

Overcoming is a peculiar and puzzling concept. It means transcending, disavowing, rising above, conquering. Joy or grief *overcomes* us. An army *overcomes* its enemy. Whoopi Goldberg *overcomes* dyslexia.

I believe in success and failure, resistance and resilience. I've felt the weight of ableism, transphobia, and homophobia and witnessed the force of poverty and racism. I know about the refusal to give up and the trap of low expectations. I have a stake in access, interdependence, community, and fierceness mixed with luck and the hardest of work. I understand that survival sometimes depends on staying silent and hidden; other times, on claiming identity and pride. But overcoming mystifies me.

That concept requires dominating, subsuming, defeating something. Pairing disabled people with overcoming imagines disability as that thing. But how could I dominate my shaky hands, defeat my slurring tongue, even if I wanted to? How could Whoopi Goldberg subsume her dyslexia even as words waver and reverse on the page?

.....

The chorus of a protest song echoes through my head: "Oh, deep in my heart / I do believe / We shall overcome / someday." This version of overcoming sung at Black civil rights protests and adopted by activists in a variety of social change movements since the 1960s means something different: collective action, transcending and dismantling white suprem-

acy and poverty, believing in and working toward a future of liberation. But what this song doesn't mean is equally telling. It doesn't urge people into a future without, beyond, or in spite of Blackness. Without making an analogy between racism and ableism, the civil rights movement and disability politics, I want to note the striking contrast between "We Shall Overcome" and the FBL's "Overcaem dyslexia." The first grapples with systems of oppression; the second, with individualized body-mind conditions.

Sometimes disabled people overcome specific moments of ableism—we exceed low expectations, problem-solve lack of access, avoid nursing homes or long-term psych facilities, narrowly escape police brutality and prison. However, I'm not sure that overcoming *disability* itself is an actual possibility for most of us. Yet in a world that places extraordinary value in cure, the belief that we can defeat or transcend body-mind conditions through individual hard work is convenient. Overcoming is cure's backup plan.

Hope in Motion

Cure is inextricably linked to hope. I'm remembering a documentary called *Christopher Reeve: Hope in Motion* about the late, famed actor who became a quadriplegic in a horse-riding accident.² As a self-appointed spokesman for cure, Reeve repeatedly expressed this link, never failing to make me angry. In the film, he brashly dismisses disabled people who question the notion of cure, saying, "There are some people who just really don't dare to hope."

I'll be blunt: *Christopher Reeve: Hope in Motion* strikes me as propaganda. The narrator uses the words *overcome*, *fight*, *determination*, *inspirational*, *unwavering will*, *working tirelessly*, *amazing results* more times than I care to count. As these words pile one on top of another accompanied by rising violin music, the film reveals itself as another over-the-top story about a tragically disabled man who beats the odds, overcomes his paralysis, and through his courageous struggle gives us hope and inspiration. There is nothing unusual here, just the same old stereotypes.

The camera follows Reeve as he works out, grinding through his daily physical therapy routines, swimming in rehab pools, elated by his occasional water-assisted step. He grimaces, laboring, flashing quick

smiles of triumph, always surrounded by a team of therapists, nurses, and aides.

The camera follows him as he chooses experimental surgery to implant a pacemaker in his abdomen with the hope that he might be able to breathe without a ventilator. His surgeon, Raymond Onders, says, "Our goal is to allow a patient to breathe the way he was born to breathe, to breathe more normally through the use of his own diaphragm." His words epitomize cure rhetoric, medical intervention returning body-minds deemed abnormal to their natural states of being, judging one piece of technology more normal than another. Relentlessly Reeve prepares for cure.

For a moment, I let go of my anger. *Christopher, what did you miss the most? Gripping a horse between your knees, feeling her supple muscles move against your legs, following and directing her rhythm with that wordless language of shifting weight and pressure? Walking on a set, a particular turn of hip and shoulder cuing the next line? Cavorting with your children and wife away from the camera?* I imagine his loss as deep as his drive for a cure.

The camera follows him around the globe as he advocates, lobbies, and fund-raises for stem cell research and a cure for spinal cord injuries. Repeatedly he enlists the rhetoric of hope and conquering diseases, leveraging pity and tragedy to make his case. *Christopher, how often did strangers pat your head? Did their pity ever exhaust you?*

.....

His story is as much about wealth, whiteness, and male privilege, about great and infuriating entitlement, as it is about disability. He claims that "the most disabling thing about being disabled is a feeling of hopelessness." He means despair about his ongoing paralysis, not the ableist violence, isolation, poverty, and lack of education and employment faced by many disabled people. He says on the eighth anniversary of his accident: "I was forty-two when I was injured, and now I'm fifty. How long is it really going to be until human trials? Will they happen here, or will I have to go overseas? I don't want to be a senior citizen when I'm cured. To get up, only to crawl around in my old age." Only a wealthy white man with a beautiful white woman at his side could possess this much entitlement. Yet, not far beneath his words, I hear the fear of body-mind change, aging, and death.

Halfway through the documentary, Reeve surprises me. He sits in

a rehab room surrounded by medical machinery, focusing hard as he learns to breathe with his new pacemaker, working to time his inhale to the pulse of this little electrical box. The narrator tells us that for eight vent-using years Reeve had no sense of smell, her tone meant to evoke pity and sympathy, to confirm his obvious pursuit of hope through cure. Breathing without his vent, he asks for a smell challenge. After he closes his eyes, a woman tips an open can of Folgers ground coffee under his nose. As violin music rises in the background, he identifies coffee, a smile emerging on his face. Then an orange, skin broken open, and finally chocolate mint. Of course, the film is telling that oh-so-familiar story, a story told thousands of times—the disabled person miraculously recovering, learning to walk, talk, see, hear, or, in this case, smell again. It reaffirms the tragedy of disability, the need for cure. At the same time, something compels me to pay closer attention as Reeve relishes those familiar scents. He says, “I don’t think at the beginning of my injury that I would have ever realized how much one thing would matter, the ability to smell, the ability to eat. . . . I was looking at the big picture—what’s the quickest research that’s going to get me up and back on a horse. . . . But the little changes . . . to be able to smell, I’m surprised by how satisfying those little discoveries are.” In this moment he isn’t renouncing cure and its link to hope, but he is grappling with the nuances of body-mind loss.

Christopher, you were a privileged, wealthy, lucky disabled person. That is until your luck ran out, and you died of an out-of-control infection. In the end, I wish you could have found hope through your disabled body-mind, through community, through a desire for social justice. Instead ableism intertwined with your great sense of entitlement and made cure irresistible.

Rebelling against Cure

Over the years, I have ranted repeatedly about cure and the medicalization of disabled people. For decades, disability activists have been saying, “Leave our body-minds alone. Stop justifying and explaining your oppressive crap by measuring, comparing, judging, and creating theories about us.” Declaring disability a matter of social justice is an important act of resistance—disability residing not in paralysis but in stairs without an accompanying ramp, not in blindness but in the lack of braille and

audio books, not in dyslexia but in teaching methods unwilling to flex. In this declaration, disability politics joins other social change movements in the ongoing work of locating the problems of injustice not in individual body-minds but in the world.

Christopher Reeve has frequented my rants. As a rich, white man with a whole lot of access to the media and lawmakers, we needed him to advocate for social justice. He could have talked about education, unemployment, and disability access, about Medicaid funding for community-based living and the problem of warehousing disabled people in nursing homes, about stereotypes and lies, about violence, police brutality, isolation, and poverty. But he didn't.

At the same time, my ranting neither begins nor ends with Reeve. In his quest for cure, he followed the lead of many disability charity organizations that use a fraction of their money to build ramps, buy wheelchairs, revamp schools. They're not funding an end to ableism. Rather they're raising money for research and cure. They shamelessly use pity, tragedy, and the belief that we would all be better off without disability.

To escape this quagmire—pity curling into violence, charity laced with the impulse to do away with disability—many of us have chosen rebellion. I for one have honed the blunt art of ranting.

.....

One day in my work as an activist-writer, I'm at a podium, debunking lies about disability and cure, ranting yet again about Reeve. I pause, look at the audience, and see my friend P. standing at the back of the room. Her story of surviving cancer—surgery, chemo, radiation, her brush with death—flashes through me. All at once, my words feel like empty rhetoric. I have no idea what cure means to her.

Later I go to dinner with her and a half dozen other people to continue the conversation. I don't know what to expect. I feel nervous, not quite ready. Over food, our talk turns to story. My friend P. tells us how she's been encouraged in dozens of ways to think about her life with cancer as a battle. She says, "I'm not at war with my body, but at the same time, I won't passively let my cancerous cells have their way with me." We talk about healing and recovery, surviving and dying. No one invokes hope or overcoming. I sit here listening. For now, my impulse to rant has vanished.

The Restoration of Health

As an ideology seeped into every corner of white Western thought and culture, cure rides on the back of *normal* and *natural*. Insidious and pervasive, it impacts most of us. In response, we need neither a whole-hearted acceptance nor an outright rejection of cure, but rather a broad-based grappling.

The American Heritage Dictionary defines cure as the “restoration of health.” Those three words seem simple enough, but actually *health* is a mire. Today inside white Western medicine, health ranges from individual and communal body-mind comfort to profound social control. Between these two poles, a multitude of practices exist. Health promotes both the well-being sustained by good food and the products sold by the multimillion-dollar diet industry. Health endorses both effective pain management for folks who live with chronic pain and the policed refusal to prescribe narcotic-based pain relief to people perceived as drug-seeking. Health both saves lives and aggressively markets synthetic growth hormones to children whose only body-mind “problem” is being short.

Amidst these contradictions, I could try to determine who’s healthy and who’s not, acting as if there might be a single objective standard. I could struggle to clarify the relationship between health and disability. I could work, as many activists and healers do, to redefine health, moving toward theories and practices that contribute to the well-being of entire communities. But in using the *American Heritage Dictionary* definition as a springboard, I actually want to move away from this mire altogether and follow the word *restoration*.

To restore a house that’s falling down or a tallgrass prairie ecosystem that’s been devastated is to return it to an earlier, and often better, condition. In this return, we try to undo the damage, wishing the damage had never happened. Talk to anyone who does restoration work—carpenters who rebuild 150-year-old neglected houses or conservation biologists who turn agribusiness cornfields back to tallgrass prairie—and they’ll say it’s a complex undertaking. A fluid, responsive process, restoration requires digging into the past, stretching toward the future,

working hard in the present. And the end results rarely, if ever, match the original state.³

Restoring a tallgrass prairie means rebuilding a dynamic system that has been destroyed by the near extinction of bison, the presence of cattle, and generations of agribusiness farming and fire suppression. The goal isn't to re-create a static landscape somehow frozen in time, but rather to foster dynamic interdependencies, ranging from clods of dirt to towering thunderheads, tiny microbes to herds of bison. This work builds on knowledge about and experience with an eight-thousand-year-old ecosystem, of which only remnants remain—isolated pockets of leadplants, milkweed, burr oaks, and switchgrass growing in cemeteries and on remote bluffs, somehow miraculously surviving. The intention is to mirror this historical ecosystem as closely as possible, even though some element is bound to be missing or different, the return close but not complete.

The process of restoration is simpler with a static object—an antique chair or old house. Still, if the carpenters aren't using axe-hewn timbers of assorted and quirky sizes, mixing the plaster with horse hair, building at least a few walls with chicken wire, using newspaper, rags, or nothing at all for insulation, then the return will be incomplete. It will be possibly sturdier and definitely more energy efficient, but different from the original house.

.....

I circle back to the ideology of cure. Framing it as a kind of restoration reveals the most obvious and essential tenets. First, cure requires damage, locating the harm entirely within individual human body-minds, operating as if each person were their own ecosystem. Second, it grounds itself in an original state of being, relying on a belief that what existed before is superior to what exists currently. And finally, it seeks to return what is damaged to that former state of being.

But for some of us, even if we accept disability as damage to individual body-minds, these tenets quickly become tangled, because an original nondisabled state of being doesn't exist. How would I, or the medical-industrial complex, go about restoring my body-mind? The vision of me without trembling hands and slurred speech, with more balance and coordination, doesn't originate from my visceral history. Rather it arises from an imagination of what I should be like, from some definition of *normal* and *natural*.

Walking in the Prairie

My friend J. and I walk in the summer rain through a thirty-acre pocket of tallgrass prairie that was not so long ago one big agribusiness cornfield. We follow the path mowed as a firebreak. He carries a big, flowered umbrella. Water droplets hang on the grasses. Spider webs glint. The bee balm hasn't blossomed yet. He points out the numerous patches of birch, goldenrod, and thistle. The first two belong here but need to be thinned out. The thistle, on the other hand, should be entirely uprooted. The Canada wild rye waves, the big bluestem almost open. Clusters of sunflowers brighten the rainy day. We pause to admire the cornflowers and asters. The songbirds and butterflies have taken shelter. For the moment, all is quiet. Soon my jeans are sopping wet from the knees down. This little piece of prairie is utterly different from a cornfield.

A whole group of people, including J., worked for over a decade to restore this land. With financial and material help from Wisconsin's Department of Natural Resources, they mowed and burned the cornfield. They broadcast the seed—sack upon sack of the right mix that might replicate the tallgrass prairie that was once here. They rooted out thistle and prickly ash. They saved money for more seed, working to undo the two centuries of environmental destruction wreaked by plows, pesticides, acres upon acres of soybeans and corn.

The Department of Natural Resources partners with this work precisely because the damage is so great. Without the massive web of prairie roots to anchor the earth, the land now known as Wisconsin is literally draining away. Rain catches the topsoil, washing it from field to creek to river to ocean. Prairie restoration reverses this process, both stabilizing and creating soil. J. and his friends worked hard, remembering all the while that neither they nor the dairy farmer down the road owned this land. It was stolen a century and a half ago from the eastern Dakota people. The histories of grass, dirt, bison massacre, genocide live here, floating in the air, tunneled into the earth.

During my visits to see J., I have taken this walk a dozen times over the last fifteen years—at noon with the sun blazing, at dusk with fireflies lacing the grasses, at dawn with finches and warblers greeting the day. My feet still feel the old cornfield furrows.

.....

As we return to the farmhouse, I think about *natural* and *unnatural*, trying to grasp their meanings. Is an agribusiness cornfield unnatural, a restored prairie natural? How about the abundance of thistle, absence of bison, those old corn furrows? What was once normal here; what can we consider normal now?

Or are these the wrong questions? Maybe the earth just holds layer upon layer of history.