

# Brilliant Imperfection

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Eli Clare is a poet, writer, activist and educator. Eli gave a talk titled, ‘Brilliant Imperfection Amidst the Pandemic’, as part of the public programmes for Rupert’s exhibition, *Other Rooms*, 2020. More information [here](#). This text is an extract from Eli’s book, *Brilliant Imperfection: Grappling With Cure* (2017).

## *Troubled and Troubling Body-Minds*

The trouble that the network of diagnosis, treatment, management, rehabilitation, prevention, and cure revolves around is multidimensional. Within a white Western worldview, many body-minds contain trouble. Or they are defined entirely by trouble. Or they cause trouble. Or they are deemed both troubled and troubling.

These notions raise the question: which realities are defined as trouble by whom and for whose benefit? The answers extend far beyond exam rooms and research labs, public health policy and diagnostic codes. This query requires us to think about power and privilege, corporate greed and medical understanding. It touches on the intimate relationships we have with our own body-minds. It engages with realities played out in schools, prisons, and emergency rooms.

*The answers can be straightforward and widely agreed on.*

Culturally, scientifically, and materially in the dominant system of medicine in the United States, certain body-mind conditions have been easily defined as trouble—a common cold as inconvenient, bronchitis as more urgent, and pneumonia as plainly dangerous. Almost no one will disagree with these assessments. Defining body-mind trouble is seemingly simple and intuitive.

*But this simplicity is a façade.*

The medical-industrial complex declares muscular dystrophy to be nothing but trouble, apparently as clear-cut as pneumonia. Yet this

pronouncement is simple only if we disregard voices from inside disability communities. Listen again to Harriet McBryde Johnson, born with a neuromuscular condition similar to muscular dystrophy:

‘At age 15, I threw away the back brace and let my spine reshape itself into a deep twisty S-curve. Now my right side is two deep canyons. . . . Since my backbone found its own natural shape, I’ve been entirely comfortable in my skin. . . . I used to try to explain that . . . I enjoy my life, that it’s a great sensual pleasure to zoom by power chair on these delicious muggy streets, that I have no more reason to kill myself than most people. But it gets tedious. . . . Most people don’t want to know. They think they know everything there is to know just by looking at me.’ <sup>1</sup>

If she and the many other disabled people who claim comfort, pleasure, and value in our lives were heeded, it would be much more difficult, maybe impossible, to cast muscular dystrophy as unmitigated trouble to eradicate.

*Too often the medical-industrial complex names our visceral experiences trouble regardless of what we know about our own body-minds. But sometimes this dynamic shifts.*

[...]

On the one hand, people with muscular dystrophy resist the notion of body-mind trouble as it is repeatedly foisted on them, and on the other hand, people with ME/CFDS [myalgic encephalomyelitis/chronic fatigue immune dysfunction syndrome] work overtime to have their body-mind trouble acknowledged while doctors and the media ignore and trivialize it. These two dynamics appear to be opposites, but actually they converge, pivoting on the ways the medical-industrial complex wields authority and dismisses what we know about our own visceral experiences.

*Indeed, who defines which realities as body-mind trouble? Sometimes the answers are multiple and conflicting.*

I think of the contentious issue of height, especially boyhood shortness. Is being too short body-mind trouble, particularly in the absence of health issues (however they might be defined) and material conditions such as malnutrition? The answers are conflicting. Eli Lilly, makers of synthetic human growth hormone (HGH), has one answer. Some doctors and parents agree with the pharmaceutical company; others don't. Short statured people, both children and adults, have a mix of answers. The organization Little People of America has yet another response.

*At best, the determinations of body-mind trouble are fraught.*

So much hangs on these definitions, including millions of dollars of profit. Over the last sixty years, the pharmaceutical corporations that sell HGH have framed shortness as grave trouble that must be addressed as early as possible in a child's—particularly a boy's—life. They've actively worked to expand the market for their drugs, shifting the criteria used to determine who is unacceptably short. In 2003 Eli Lilly petitioned the U.S. Food and Drug Administration (FDA) and won approval to sell HGH for use not only by children who are short because of a diagnosable “disorder” but also by those in the bottom 1.2 percent of height for their age group. This change added 400,000 potential customers to Eli Lilly's market. Three years after this decision, the HGH drug Humatrope made \$460 million, up 40 percent from 2002.<sup>2</sup> All of this means that redefining the body-mind trouble of shortness increased Eli Lilly's earnings by \$130 million.

*Sometimes the response to the question, which realities are defined as trouble by whom and for whose benefit?, is transparent. And other times, the answers are considered so intuitively obvious that no one bothers to articulate them.*

I think of heterosexuality, whiteness, and wealth, particularly when two or more of these conditions exist together. The high rates of neglect and violence in heterosexual nuclear families could easily be defined as trouble. The multigenerational delusion that white people hold about our superiority could definitely qualify as trouble. The hoarding of resources in upper-middle-class and upper-class homes,

as reflected by an overabundance of clothing, cars, houses, food, money, and lavish vacations, could undoubtedly meet the criteria for trouble. And yet the “heterosexual nuclear family disorder,” the “white entitlement syndrome,” and the “wealthy greed dysfunction” haven’t been invented.<sup>3</sup> Nor do I actually want them to be. Disorder, syndrome, and dysfunction have been used against far too many people.

Still heterosexuality, whiteness, and wealth simply aren’t defined as trouble. I feel almost silly writing something so obvious. And yet in a world where queer and trans people, people of color, and poor people pay an intense price every day for being deemed troubled and troubling, this obvious state of affairs needs to be called out. Queer and trans youth are kicked out of their families and homes. Immigrants of color are detained and deported in record numbers. Black men are four times more likely than white people to be diagnosed with schizophrenia. Poor people are called lazy, shiftless, and demonized for their poverty. The consequences for being deemed troubled and troubling pile up fast. And through it all, heterosexuality, whiteness, and wealth escape undiagnosed, no one locked up or kicked out solely because they’re straight or white or rich.

*Many answers to the question of who defines which realities as body-mind trouble are bound up with power and privilege.*

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The relationship between cure and trouble is entirely enmeshed. In *Normal at Any Cost*, the journalists Susan Cohen and Christine Cosgrove tell the story of HGH, Eli Lilly, and how girlhood tallness and boyhood shortness became known as trouble. Midway through the book, they write, only partly tongue in cheek, “Sometimes cures went in search of diseases.”<sup>4</sup>

If muscular dystrophy wasn’t deemed trouble, the last fifty years of research sponsored and encouraged by the Muscular Dystrophy Association wouldn’t exist. If being gay, lesbian, or bi wasn’t defined as trouble, ex-gay conversion therapy wouldn’t exist. If being a person of color wasn’t considered trouble, skin lighteners wouldn’t

exist. And if synthetic HGH didn't exist, "non-growth-hormone-deficient short stature" (the phrase Eli Lilly used at the FDA hearing) wouldn't be framed as trouble. <sup>5</sup>

Cure both depends on and creates body-mind trouble in all of its different forms.

### *Variations on Cure*

Once the medical-industrial complex has defined, named, or created trouble, we as clients, patients, and consumers don't face a singular monolithic intervention. As an ideology, cure presents an inflexible set of values. But as a multifaceted and contradictory practice, it multiplies into thousands of different technologies and processes. Each variation comes with its own cluster of risks and possibilities.

Some medical technology works most of the time for most people. The use of antibiotics for infection, synthetic insulin for diabetes, synthetic estrogen and testosterone for trans folks who need or want to reshape our gendered and sexed body-minds all produce reliable and consistent results.

Other kinds of technology offer glimmers of possibility but present high risks or ambiguous outcomes. Will chemotherapy and radiation eradicate the cancer, push it into remission, buy a bit more time, or just create more misery? Will operating on the brain tumor stop the seizures and end the brain-exploding pain, or will it decrease the pain a bit and probably cause vision impairment?

Still other cures and treatments are boondoggles or experiments. When the growth hormone treatment, the hip-stabilizing operation, the \$1,000-per-month regimen of vitamins and herbs goes awry, leaving us chronically ill, even more mobility impaired, or in debt, we sometimes reflect back and pinpoint how we were taken for a ride. Or we feel gratitude for the risk that changed our body-minds for the better.

And then there are the imaginary cures. I think of my parents' unending desire to repair me. It was nothing but a fantasy fueled by

shame and grief. Although the medical-industrial complex has been known to manipulate people's hopes and desires, no one, except the evangelical Christians who prayed over me, ever offered my parents the possibility of an actual cure for mental retardation or cerebral palsy. Pure imagination drove my mother and father.

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The medical-industrial complex is unwavering in its commitment to cure's ultimate goal—ensuring that body-mind trouble no longer exists as if it had never existed in the first place. Yet in practice there is a routine acceptance of potential cures, partial cures, and failed cures. I think of fat people and all the technology designed to make them slender: fad diets, prescription weight loss drugs, gastric bypass and lap band surgeries. In a fatphobic culture, it doesn't seem to matter that dieting, more often than not, results in weight cycling rather than long-term weight loss. Nor does it matter that surgery outcomes range widely—from death to permanent difficulty with eating, nutrition, and digestion; from significant long-term weight loss to weight loss followed by weight gain. The quest for slenderness, for an eradication of fatness, is seemingly worth all the failures, dangers, dubious medical procedures, and direct harm.

The unquestioned value placed on cure in general provides cover for all the variations, whether they be reliable, risky, ambiguous, experimental, boondoggles, or imaginary. And when cure plainly fails, we—the consumers, clients, or patients—are often blamed, either subtly or blatantly, for these failures. We didn't try hard enough. We were lazy. We were drug resistant. We were noncompliant. Or we're told that if only we wait, a reliable cure will emerge sometime in the future. Somehow, amidst it all, the very notion of cure remains undisputed.

### *Skin Lighteners and Hot Springs*

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The tools of cure include cochlear implants and skin bleaching creams, vaccinations and hot springs. Many of these technologies are

embedded in the medical-industrial complex—produced by pharmaceutical corporations; matched with users through diagnosis and treatment; shaped by researchers, doctors, and health insurance companies; and distributed by pharmacists. However, cure also extends beyond what is considered medical, some of its tools existing in cosmetic drawers and spas.

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Skin bleaching products are designed to answer the trouble of dark skin. Sociologist Amina Mire lays it out clearly: “Throughout western colonial history . . . the dark body has been represented [by the dominant culture] as the least virtuous and aesthetically least appealing. . . . Constructing colonized people’s culture and body images as pathological, backward and . . . ugly has been central to . . . white supremacy.” In other words, the trouble of skin color is created fundamentally through racism and bolstered by the medical-industrial complex’s notion of pathological.

In cure’s long tradition, this declaration of trouble paves the way for selling repair. Feminist scholar Margaret Hunter writes, “Women and men of color have ever-increasing opportunities to alter their bodies toward whiteness. They can purchase lighter-colored contact lenses for their eyes; they can straighten kinky or curly hair; they can have cosmetic surgeries on their lips, noses, or eyes. But one of the oldest traditions of this sort is skin bleaching.” Products used for this purpose are called Ambi Fade Cream, Esotérica, Porcelana, Vantex, Venus de Milo. They are claimed to lighten, brighten, and whiten the skin. They are marketed to dark-skinned women of color with taglines like “Fair and Lovely” and increasingly to dark-skinned men of color with promises like “Fair and Handsome.” Sold exclusively as beauty aids, some of these creams are nonetheless available only by prescription, existing on the boundary between cosmetics and pharmaceuticals. Many of them are made with toxic, body-mind-damaging chemicals strictly regulated or banned by the FDA. But ultimately they are only loosely connected to the medical-industrial complex, in need of neither diagnostic categories nor medical authorization to sustain themselves.

The market for these creams is rooted in racist-sexist definitions of beauty and depends on women (and men) of color who have internalized the notion that the darkness of their skin is wrong and troubling. One twenty-two-year-old, when asked why she's willing to risk her health to lighten her skin, responds, "I want people to think I am more than a ghetto girl. . . . I want to walk into dance halls and feel like a movie star, a white one." To be blunt, the manufacturers of skin lighteners profit from shame.

The products and treatments sold to us to fix what is deemed broken, wrong, or shameful range widely. Some, like skin lighteners, are designed for this purpose. Others, like hot springs and fresh air, are adopted.

I think of the water in Warm Springs, Georgia, and Saratoga Springs, New York; the air in Brattleboro, Vermont, and Saranac Lake, New York. Disabled and sick people with enough money to travel have long taken to the road, looking for cure, comfort, or both. They've landed at the Georgia Warm Springs Foundation, the Brattleboro Hydropathic Establishment, the Adirondack Cottage Sanitarium, the Roosevelt Bathhouses. Water bubbles hot from the ground, oozes up laden with calcium bicarbonate, sodium chloride, carbon dioxide. Air wafts fresh and cool. Travelers have arrived to soak, breathe, and restore.

At Warm Springs, they occupied hospital beds for months at a time, coped with multiple surgeries, cried themselves to sleep at night, wrestled with pain, misery, loneliness. They completed their physical therapy routines in pools heated by the springs. Some polio survivors relearned to walk; many did not. At Saranac Lake, they rested eight hours a day outside on porches, breathing the air that supposedly cured tuberculosis. Some of them lived; others died. At Brattleboro, they lay wrapped in water-soaked sheets, shivering and sweating, drank gallons of water, floated in private baths, lived half their time outdoors, taking in the good air. Some left revived, feeling better for their sojourn; others did not.



The Kanien'kehá:ka (Mohawk), Creek, Cherokee, and Abenaki used to frequent these places, lie in their waters, each nation with its own healing rituals and spiritual traditions. On this land, white people have built resorts frequented by other white people; employed African Americans as cooks, maids, chauffeurs; sold physical therapy, water therapy, fresh-air therapy. At the same time, many Indigenous peoples have been removed from these homelands. They've died of tuberculosis and smallpox; become disabled by war, hunger, poverty, alcohol, heartsickness. They've continued on, practicing and adapting their traditional systems of medicine.

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I take a trip to Saratoga Springs, wanting to indulge in a long warm soak. Hot water relaxes my body-mind in a way that nothing else does, tremor and tension dissolving into the heat. I join the many people who, over the centuries, have flocked to these mineral baths. I expect the New Age aroma therapy and the outlandish hourly rates but not the big, old brick buildings that look like state-run hospitals and psych facilities.

I stop at a bathhouse built in 1935, named after the first, and to-date only, wheelchair-using U.S. president, who had an abiding interest in the power of water to cure. After his bout with polio, Franklin D. Roosevelt took to the road both hopeful and desperate, following rumors of healing waters at a resort in Warm Springs, Georgia. It only took him a few days in the eighty-eight-degree pools to declare progress after years of searching. A wealthy, white northerner, he bought the seventeen-hundred-acre resort in 1927, transforming it into a rehabilitation center and gathering spot for white polio survivors. The old photos show rooms full of disabled people and their mobility equipment—high-backed wheelchairs, canes and crutches, rolling beds, braces. Everyone is white, except the people cooking and cleaning. Black polio survivors went to Tuskegee, Alabama. Although he never found a cure, Roosevelt surely benefited from that disability accessible community and the warm, buoyant waters running under Pine Mountain. Years later as president, he helped find

the money to fund the building of bathhouses near the curative waters of Saratoga Springs in his home state.

Stepping into the still-open-and-operating Roosevelt Bathhouse, my gait lopsided and rattling, I wonder if the staff thinks I'm yet another traveler, desperate to "take the cure." I'm looking for comfort and the delicious feeling of warm mineral water on my skin, but they may expect I want to be fixed. I've left my crip pride button at home.<sup>10</sup> A wooden wheelchair, wool blanket draped over one arm, decorates the lobby, even though there are two steps to get in and no sign of a ramp. Nor do I see any acknowledgment that we are on Kanien'kehá:ka land. The woman at the front desk tells me she has no more openings for the day. It's just as well. I don't really want to spend money at this place that turns a profit by selling mineral water from deep inside the planet, capitalizing on our need for comfort and desire for cure.

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Encounters with the ideology of cure can be as daily as a cosmetic cream and as comforting as a long soak in hot mineral water, as life-saving as antibiotics and as difficult as chemotherapy, as nonmedical as the fresh air in Brattleboro and Saranac Lake and as medicalized as liver transplant surgery. No one technology epitomizes this ideology. Rather it latches on to many different tools, some of them as old as the planet and others on the cutting edge of science.

<sup>1</sup> Johnson, Harriet McBryde. *Too Late to Die Young: Nearly True Tales from a Life*. New York: Picador, 2005. pp. 1–2.

<sup>2</sup> Cohen, Susan and Christine Cosgrove. *Normal at Any Cost: Tall Girls, Short Boys, and the Medical Industry's Quest to Manipulate Height*. New York: Tarcher/Penguin, 2009. pp. 279–81, p. 351.

<sup>3</sup> A telling exception is the use of affluenza, which was leveraged in a 2013 court case to defend Ethan Couch, a rich white teenager who killed four people in a drunk-driving accident. The Guardian describes affluenza in this context as "indicating that [Couch's] behavioural problems were influenced by a troubled upbringing in a wealthy family where privilege prevented him from grasping the consequences of his actions" (Dart, "Texas Teenager Suffering 'Affluenza' Avoids Jail for Second Time"). This "disorder," not officially recognized by the medical-industrial complex, is being used here not to define wealth or class privilege as body-mind trouble but to protect a rich white teenage boy. Thanks to Alison Kafer for bringing affluenza to my attention and helping me think about it.

<sup>4</sup> Cohen and Cosgrove, *Normal at Any Cost*, p. 65.

<sup>5</sup> For more details about the FDA hearing, see Cohen and Cosgrove, *Normal at Any Cost*, pp. 269–305.

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