

Eli Clare

Brilliant Imperfection: Grappling with Cure
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In *Brilliant Imperfection: Grappling with Cure*, Eli Clare examines how the ideology of cure functions within our social imaginary, informing everyday interactions as well as medical research and practice. He disrupts the often unquestioned assumption that cure is always necessary and desirable. Rather than engaging in an outright rejection of cure, he details his own struggle to reckon with his ambivalence toward medical interventions. In line with the book's subtitle, Clare invites readers to truly *grapple* with cure. He asserts, "Cure saves lives; cure manipulates lives; cure prioritizes some lives over others; cure makes profits; cure justifies violence; cure promises resolution to body-mind loss" (xvi). Clare delves into these facets of cure, blending historical analysis, poetry, and personal narrative in order to clarify how the ideology of cure functions at structural and individual levels. He adopts the term *body-mind* to capture the interconnectedness of our bodies and minds as well as the separation that the ideology of cure often assumes in privileging the mind over the body (xvi). Clare characterizes *brilliant imperfection* "[a]s a way of knowing, understanding, and living with disability and chronic illness" that values body-mind difference (xvii).

Chapter 1 introduces the narrative of Clare's birth and initial encounter with medical intervention, with this line: "I tell this story not as a tragedy, but a truth, a shrug of the shoulders, water over rock" (5). This line provides a powerful framing for the entire book; he shares stories that refuse assimilation into dominant tropes of disability as either a tragedy or an obstacle to be overcome. Clare uses his own case as an example to illustrate the incoherence of the notion of overcoming disability at the level of the individual, asking: "how could I dominate my shaky hands, defeat my slurring tongue, even if I wanted to?" (9). His claim is not that disability has no material implications; rather, he demonstrates that, for many people, it matters in ways that differ significantly from the expectations of most nondisabled people.¹ Like many other members of disability communities, he asserts that his body-mind is central for his identity, including trembling hands and slurred speech. Rather than locating individual body-minds as the primary or only targets for intervention, Clare calls for social change to address factors that reduce the ability of disabled people to flourish.

In chapter 2, Clare details how medicine, science, the academy, and the state have long appealed to the concept of *defectiveness* in order to vindicate policies and practices. He identifies the

notion of defectiveness as ableist in nature, but he notes that it undergirds many forms of oppression. Clare provides examples as wide-ranging as slavery, immigration policy, ex-gay conversion therapy, selective abortion, and racism in psychiatry. This chapter includes discussion of three approaches the medical-industrial complex takes to eliminating defects. Body-minds declared defective, which may include being denied personhood, are made vulnerable to violence. Clare concludes that, rather than being a contingent phenomenon, "as a widespread ideology centered on eradication, cure always operates in relationship to violence" (28). His concern extends to violence humans enact on nonhuman animals and the earth.

Chapter 3 focuses on the functions of diagnosis. Clare acknowledges that diagnosis can be helpful for making sense of experiences and facilitating various sorts of access. Nonetheless, he is concerned with how diagnosis can lead to violence under the guise of care (47-48). Clare focuses on Fairview Hospital and Training Center and Judge Rotenberg Educational Center (JRC), institutions whose reported practices would be considered child labor, abuse, or even torture in other contexts, but are classified as treatment through diagnosis.² In his words: "I'm inviting us to think about what diagnosis does, because this system not only describes those of us deemed defective, deficient, or disordered in a million different ways but also helps shape how the world treats us" (42). Since diagnosis can have such a significant impact on the lives of individuals and groups, it is crucial to identify the ways it is related to social structures and whose interests it serves.

In chapter 4, Clare wonders how to determine the meanings of natural and unnatural in a world in which variations such as facial birthmarks are considered "abnormal," and exposure to war, toxic chemicals, and environmental racism damage body-minds. He raises the question of how to best oppose the harm environmental destruction entails without reinforcing ableism. He seeks an answer that will draw attention to harmful and unjust practices while affirming the value of chronically ill and disabled people. Here is one of several places in the text that Clare actively grapples with his own position on cure, presenting perspectives of people with disabilities and chronic illnesses who simultaneously call for social justice and medical cures.

Clare suggests in chapter 5 that the commonality between the seemingly divergent experiences of a person with muscular dystrophy--who wants people to recognize that her lived experience is irreducible to her diagnosis--and a person with myalgic encephalomyelitis/chronic fatigue immune dysfunction syndrome--who just wants her symptoms to be taken seriously--is that the medical-industrial complex deems their claims incredible (72-73). He introduces the notion of the *trouble*, which refers to "the perception of a disease, infection, virus, chronic illness, dysfunction, disorder, defect, abnormality, or body-mind difference" (70). Clare examines the relationship between capitalism and cure in a world in which corporations have tremendous influence over what body-minds are counted as trouble, a broader category than diagnosis (78). He asks the reader to consider how power and privilege shape whether body-minds are defined as trouble, noting that being considered "too short" or having skin that is "too dark" may be, but belief in white supremacy is not. Cosmetic and pharmaceutical companies manipulate our desires and promise their fulfillment through pills, creams, and chemicals. He makes the further distinction between cure as an ideology and cure as a practice.³ Both require body-minds defined as trouble.

Chapter 6 highlights structural issues that control access to cure and how faith in future cures can lead to neglect of those who will not benefit from cure. Clare notes that most disease-and-disability-related charity groups are oriented toward funding research for cures through sponsorship of athletic events. Although these types of fundraisers are intended to benefit people with chronic diseases and disabilities, he points out that they fail to address what is necessary in the present and tend to exclude disabled people as participants, while appealing to fear of disability and disease in order to motivate donors and volunteers. He contrasts this approach with that of Zoe's Race, which raises money to help families to make their homes accessible and involves a one-kilometer or five-kilometer walk, roll, or run. Clare suggests that rather than focusing exclusively on raising money for future cures, we have the option of prioritizing access over cure or devoting resources to both in order to support what people currently need.

In chapter 7, Clare seeks to re-humanize Carrie Buck, whose name is invoked in the 1927 Supreme Court case *Buck v. Bell*. By imagining what Buck might say about her experiences, he refuses the reduction of her life to a court case and a medical case file. Clare points out that in *Three Generations, No Imbeciles* (Lombardo 2008), historian Paul Lombardo seeks to vindicate the Buck family, claiming that they were not "really feebleminded" (110). This approach implies that it is tragic when people are mistakenly categorized in this way, but the institutionalization and sterilization of people with intellectual impairments is not seen as morally unacceptable. Clare is concerned about the way that the words *defective* and *feebleminded* are used to devalue body-minds. If rights are grounded in intelligence or personhood, on what grounds can those who are disqualified make claims on society?

Like disability and animal rights activist Sunaura Taylor, Clare connects the increased vulnerability imposed upon those humans labeled *monkey* with the danger nonhuman animals face within white Western domination (Taylor 2017). He maintains, "Throughout the nineteenth century and beyond, racism, colonialism, and ableism have been coiled together inside the word *monkey*" (116). On Clare's account, the dehumanization that *monkey*--not only the term itself, but the way of thinking it symbolizes--entails was the condition for the possibility of such seemingly different social phenomena as freak shows, the World's Fair, the Tuskegee Study, and dermatology experiments performed on prisoners.

When cure is not possible, prevention is often seen as the obvious answer--whether this means preventing the birth of a disabled child or preventing an already existing person from becoming disabled. In chapter 8, Clare calls this "un-choosing disability" and he contends that we all face tremendous pressure to make particular kinds of choices in order to prevent or limit disability. For instance, health-care professionals and members of the general public encourage disabled people to manipulate their body-minds--whether through surgery, psychotropic drugs, or other means--in order to conform to a nondisabled norm as closely as possible. Returning to his experiences and the diagnoses imposed upon them, Clare raises the question of what it means to claim our bodies. Dominant narratives of disability and the corresponding imperative to un-choose disability are straightforward, but lived experiences related to disability are full of messiness and ambiguity. Clare struggles with his choice to reject certain types of medical interventions and diagnoses while seeking out others. He asks us to envision a world in which it would be possible to obtain desired medical interventions without the notions of *disorder* and *defect* (142).

In chapter 9, Clare considers the power dynamics involved in the invasive questions people who are members of oppressed groups are forced to contend with on a regular basis. Although some may object that questions regarding another's identity and body are innocent, he points out that: "The endless questions and their exhausting demands only target those of us deemed abnormal and exotic" (151). He is interested in patterns within these interactions and what it means that the demand to provide an account is imposed only upon certain people.

Clare details how self-hatred and love, shame and pride coexist in his everyday life. In spite of the energy he has devoted to rejecting the assumption that his body-mind is broken, Clare wonders what it would be like if we claimed our various forms of brokenness. He states, "[T]he ideology of cure would have us believe that whole and broken are opposites and that the latter has no value" (159; italics in source). Against this, he insists that our struggles--as individuals and communities--to accept our body-minds, regardless of their characteristics and the messages we have been given about them, is worthwhile.

In concluding this text, Clare offers no resolution. Instead, chapter 10 challenges the reader to cultivate comfort with ambiguity, contradictions, unanswered questions, and the messiness of embodied existence. He attempts to articulate how self-loathing and self-love coexist in the complicated relationship between his body-mind and diagnosis and cure. Clare notes the importance of compassion and patience when attempting to understand others' body-mind experiences and choices that fly in the face of our politics.

Discussion

Although Clare is a poet and an activist rather than a philosopher, feminist philosophers stand to benefit from engagement with *Brilliant Imperfection*. Clare's approach raises philosophical questions regarding the meaning and function of concepts like *cure*, *defect*, and *monkey*. He consistently engages in intersectional analyses, considering how race, gender, class, disability, sexuality, anti-fat bias, environmental destruction, and capitalism function together in order to shape how we are oriented toward cure and how we experience our bodies. Using historical as well as contemporary phenomena, he illustrates ways that medicine can serve as a force for social control. Recognizing that parts of his discussion may entail emotional difficulty, Clare adopts trigger warnings, which he explains as a feminist practice that increases rather than restricts access (xix). This book may make our hearts ache, but it also provides evidence of resilience and reasons to hope for a better future.

Clare describes this work as a mosaic. Rather than presenting a linear narrative, *Brilliant Imperfection* meanders and revisits ideas introduced earlier in the text. This may present a challenge for readers attempting to quickly identify his position and main points. I do not necessarily consider this to be a problem, but it may inform how one reads--and especially teaches--this book. I have adopted this text in a couple of my courses. Most students planning to have a career in health care cite a desire to help patients--including by curing them--as their primary motivation. They typically have never encountered the idea that cure is not unquestionably good. Thus, I think it is important for medical students to consider how ableism undergirds the assumption that cure is always desirable.

Brilliant Imperfection is an intensely personal work. Clare's vulnerability and honesty are part of what makes it so powerful. Nonetheless, one may think that he goes too far at times. For instance, his discussion of a girl (now woman) referred to as Ashley X in the bioethics literature includes Clare's identification with Ashley (see Gunther and Diekema 2006; Kittay 2011; and Kafer 2013). He questions her father's claim that he loves her. Although the medical interventions performed on Ashley have provoked much controversy, it is certainly possible to condemn the actions of her parents and doctors without questioning their concern for her well-being. I do not know Ashley's father's disposition toward his daughter, and neither does Clare. I appreciated many of the points Clare made about the rhetoric and assumptions related to the so-called "Ashley treatment," but his accusation seems out of place.

Like Alison Kafer's *Feminist, Queer, Crip*, this text emphasizes questions related to disability and temporality. How do past ways of conceiving of disability affect contemporary understandings and practices? How do attitudes and social practices in the present affect the experiences of disabled people now, and how do they shape future possibilities? A theme running throughout this text is Clare's yearning for a world in which those of us inhabiting body-minds deemed "abnormal"--along any number of axes--will cease to be considered remarkable. In his words:

I catch glimpses of a world where many kinds of body-mind difference will be valued and no one eradicated; where comfort, pain, well-being, birth, and death all exist. Cure promises so much, but it will never give us justice. In this world reconfigured, cure may not exist, but if it does, it will be only one tool among many. (184)

He contrasts the visions of those who hope to eradicate disability and direct their resources to developing cures with those, such as himself, who desire a present that addresses the needs of disabled people and a future in which diverse body-minds are supported and valued. Clare's hope for the future lies not in cure but in the idea that disabled people will be considered ordinary and not have to struggle against oppression in order to flourish.

References

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¹ Clare uses *disability* to refer both to body-minds and social factors that shape disabled people's opportunities and experiences.

² Although Fairview closed down in 2000, JRC uses electric shocks on its patients, calling it "aversive therapy," to this day. "The commission [Inter-American Commission on Human Rights] cites the work in 2013 of the then-UN monitor on torture, Juan Méndez, who found JRC's electric shock technique was a potential violation of the UN convention against torture and other international laws." <https://www.theguardian.com/us-news/2018/dec/18/judge-rotenberg-center-electric-shocks-ban-inter-american-commission-human-rights>

³ Clare clarifies, "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 (76). He adds, "The unquestioned value placed on cure in general provides cover for all the variations, whether they be reliable, risky, ambiguous, experimental, boondoggles, or imaginary" (77).