Stolen Bodies, Reclaimed Bodies: Disability and Queerness

Eli Clare

want to write about the body, not as a metaphor, symbol, or representation, but simply as the body. To write about my body, our bodies, in all their messy, complicated realities. I want words shaped by my slurring tongue, shaky hands, almost steady breath; words shaped by the fact that I am a walkie—someone for whom a flight of stairs without an accompanying elevator poses no problem—and by the reality that many of the people I encounter in my daily life assume I am "mentally retarded." Words shaped by how my body—and I certainly mean to include the mind as part of the body—moves through the world.

Sometimes we who are activists and thinkers forget about our bodies, ignore our bodies, or reframe our bodies to fit our theories and political strategies. For several decades now, activists in a variety of social change movements, ranging from black civil rights to women's liberation, from disability rights to queer liberation, have said repeatedly that the problems faced by any marginalized group of people lie, not in their bodies, but in the oppression they face. But in defining the external, collective, material nature of social injustice as separate from the body, we have sometimes ended up sidelining the profound relationships that connect our bodies with who we are and how we experience oppression.

+ + +

Disentangling the body from the problems of social injustice has served the disability rights movement well. The dominant paradigms of disability—the medical, charity, supercrip, and moral models—all turn disability into problems faced

Public Culture 13(3): 359–365 Copyright © 2001 by Duke University Press

Public Culture

by individual people, locate those problems in our bodies, and define those bodies as wrong. The medical model insists on disability as a disease or condition that is curable and/or treatable. The charity model declares disability to be a tragedy, a misfortune, that must be tempered or erased by generous giving. The supercrip model frames disability as a challenge to overcome and disabled people as superheroes just for living our daily lives. The moral model transforms disability into a sign of moral weakness.

Of course, these differing models intersect and overlap. Take, for instance, Jerry Lewis and his Labor Day telethon. He raises money by playing to pity and promising to find a cure. This money does not fund wheelchairs, ramps, or lift bars, nor lawyers to file disability discrimination lawsuits, but research for a cure, for a repair of bodies seen as broken, for an end to disability. Lewis is strategically playing the cards of the medical model and the charity model. Or think about Christopher Reeve as he speaks out about the need to find a cure for spinal cord injuries and insists on his ability to overcome quadriplegia, going so far as to air a Super Bowl ad where, through computer-generated imagery, he is shown actually getting up out of his wheelchair and walking across a stage. Reeve creates himself as a supercrip, the superhero now playing himself offscreen, and is at the same time enmeshed in the medical model. Or consider mothers with hereditary disabilities, who face significant disapproval for their decisions to have children and immense pressure to undergo various medical tests and to consider abortion if their fetuses appear to be disabled. They are caught in a vise-grip between the moral model and medical model. Whatever the permutations, these models unambiguously define disability and disabled bodies as wrong and bad.

In resistance to this, the disability rights movement has created a new model of disability, one that places emphasis on how the world treats disabled people: Disability, not defined by our bodies, but rather by the material and social conditions of ableism; not by the need to use a wheelchair, but rather by the stairs that have no accompanying ramp or elevator. Disability activists fiercely declare that it's not our bodies that need curing. Rather, it is ableism—disability oppression, as reflected in high unemployment rates, lack of access, gawking, substandard education, being forced to live in nursing homes and back rooms, being seen as childlike and asexual—that needs changing.

+ + +

Locating the problems of social injustice in the world, rather than in our bodies, has been key to naming oppression. It has been powerful for marginalized peoples, including disabled people, to say, "Leave our bodies alone. Stop justifying

Stolen Bodies, Reclaimed Bodies

and explaining your oppressive crap by measuring, comparing, judging, blaming, creating theories about our bodies." But at the same time, we must not forget that our bodies are still part of the equation, that paired with the external forces of oppression are the incredibly internal, body-centered experiences of who we are and how we live with oppression. To write about the body means paying attention to these experiences.

Let me begin with my body, my disabled queer body. I use the word *queer* in both of its meanings: in its general sense, as odd, quirky, not belonging; and in its specific sense, as referring to lesbian, gay, bisexual, and transgender identity. In my life, these two meanings have often merged into one. *Queer* is not a taunt to me, but an apt descriptive word.

My first experience of queerness centered not on sexuality or gender, but on disability. Early on, I understood my body to be irrevocably different from those of my neighbors, playmates, siblings. Shaky; off-balance; speech hard to understand; a body that moved slow, wrists cocked at odd angles, muscles knotted with tremors. But really I am telling a kind of lie, a half-truth. "Irrevocably different" would have meant one thing. Instead, I heard: "wrong, broken, in need of repair, unacceptably queer" every day, as my classmates called out *cripple, retard, monkey*; as people I met gawked at me; as strangers on the street asked, "What's your defect?"; as my own parents grew impatient with my slow, clumsy ways. Irrevocably different would have been easy, compared to wrong and broken. I knew my body was the problem. I stored the taunting, the gawking, the shame in my bones; they became the marrow. This was my first experience of queerness.

Only later came gender and sexuality. Again I found my body to be irrevocably different. At nine, ten, eleven, my deepest sense of self was as neither boy nor girl. I knew this as I flew my kite in the hay fields and sheep pastures. I knew this as I dug fence postholes and hauled firewood with my father. I just knew this. Tomboy, genderqueer, transgender—it wasn't a stage I grew out of. My body never learned to walk in high heels; to feel strong and comfortable, even sexy, in a skirt. I never stopped feeling at home in my work boots and flannel shirts, never lost my penchant for a broad stance and direct gaze, my gender expression shaped by the loggers and fishermen I grew up among. I heard nothing about transgender and transsexual people; it seemed that folks who lived outside the gender binary—or in a complex relationship to it—didn't exist in my world. More accurately, I was the only one.

When I was twelve, I met my first dykes. I developed a sweet childhood crush and wished they would come live with me in my river valley. By the time their visit ended and they had left rural Oregon, I knew I was somehow like them. Sexually queer—it wasn't a stage I grew out of. I heard my father fall tight and silent when he talked about homosexuals. I heard rumors about the county sheriff running faggots out of town. I heard my classmates call me *lezzie* before I even knew what that word meant. All the words and all the silence settled into my body, the experience of oppression undeniably coming to live there. My irrevocably different body.

But it isn't only oppression that lives in my body, our bodies. The many experiences of who we are, of our identities, also live there. I know so clearly that my queerness, my disability, reside in my body—in the ways that I move, dress, cut my hair; in who I am attracted to and who's attracted to me; in my tremors, my slurred speech, my heavy-heeled gait; in the visceral sense of muscle sliding over muscle as I lie with my lover; in the familiarity of tension following tremor, traveling from shoulder to fingertip. Identity, of course, can live in many places all at once—in the communities we make home, the food we eat, the music we play and dance to, the work we do, the people we feel wild and passionate about, the languages we speak, the clothes we wear. But so much of who *I* am is carried in my irrevocably different body.

+ + +

Irrevocable difference could be a cause for celebration, but in this world it isn't. The price we pay for variation from the norm that's defined and upheld by white supremacy, patriarchy, and capitalism is incredibly high. And in my life, that price has been body centered. I came to believe that my body was utterly wrong. Sometimes I wanted to cut off my right arm so it wouldn't shake. My shame was that plain, that bleak. Of course, this is one of the profound ways in which oppression works—to mire us in body hatred. Homophobia is all about defining queer bodies as wrong, perverse, immoral. Transphobia, about defining trans bodies as unnatural, monstrous, or the product of delusion. Ableism, about defining disabled bodies as broken and tragic. Class warfare, about defining the bodies of workers as expendable. Racism, about defining the bodies of people of color as primitive, exotic, or worthless. Sexism, about defining female bodies as pliable objects. These messages sink beneath our skin.

There are so many ways oppression and social injustice can mark a body, steal a body, feed lies and poison to a body. I think of the kid tracked into "special education" because of his speech impediment, which is actually a common sign of sexual abuse. I think of the autoimmune diseases, the cancers, the various kinds of chemical sensitivities that flag what it means to live in a world full of toxins. I think of the folks who live with work-related disabilities because of exploitative, dangerous work conditions. I think of the people who live downwind of nuclear fallout, the people who die for lack of access to health care, the rape survivors who struggle with post-traumatic stress disorder. The list goes on and on.

The stolen bodies, the bodies taken for good, rise up around me. Rebecca Wight, a lesbian, shot and killed as she hiked the Appalachian Trail with her lover. James Byrd Jr., an African American, dragged to death behind a pickup driven by white men. Tyra Hunter, a transgendered person living as a woman, left to bleed to death on the streets of D.C. because the EMT crew discovered she had a penis and stopped their work. Tracy Latimer, a twelve-year-old girl with severe cerebral palsy, killed by her father, who said he did it only to end her unbearable suffering. Bodies stolen for good. Other bodies live on—numb, abandoned, full of self-hate, trauma, grief, aftershock. The pernicious stereotypes, lies, and false images can haunt a body, stealing it away as surely as bullets do.

But just as the body can be stolen, it can also be reclaimed. The bodies irrevocably taken from us, we can memorialize in quilts, granite walls, and candlelight vigils. We can remember and mourn them, use their deaths to strengthen our will. And as for the lies and false images: we need to name them, transform them, create something entirely new in their place. Something that comes close and finally true to the bone, entering our bodies as liberation, as joy, as fury, as a will to refigure the world.

+ + +

The work of refiguring the world is often framed as the work of changing the material, external conditions of our oppression. But just as certainly, our bodies or, more accurately, what we believe about our bodies—need to change so that they don't become storage sites, traps, for the very oppression we want to eradicate. For me, this work is about shattering the belief that my body is wrong. It began when I found communities committed to both pride and resistance. It was there that I could begin to embrace irrevocable difference—come to know the grace in my shaky hands, the rhythm of tremor and tension in my muscles, the joy in my transgendered butch body, sun on my back, a lover's hand on my belly.

The goal isn't to make irrevocable difference disappear. Certainly, my body is no less different, no less queer, than it was during the years I wanted to cut off my right arm, to be nondisabled—or, failing that, to pass. Every time I walk down a street and someone stares, trying to figure out my body, to make sense of my Stolen Bodies, Reclaimed Bodies shaky hands and slow speech, or to determine whether I'm a man or a woman and if a woman, surely a dyke—I know nothing has changed. What has changed is how I perceive my irrevocable difference, how I frame it, what context I place it into.

I am still in the middle of this work. I think of my lover cradling my right hand, saying, "Your tremors feel so good"; saying, "I can't get enough of your shaky touch"; saying, "I love your CP." Shame and disbelief overwhelm me until I stop and really listen to the words. Another layer begins to shatter. I think of a demonstration I attended several years ago with a whole crowd of disabled people. Being a gimp was the norm. We blockaded a building, shut it down, pressured a politician into supporting important legislation. At the end of the day, I went to sleep adoring irrevocable difference. I think of a book of portraits of lesbian, gay, bisexual, and transgendered writers. I look again at my friend Kenny, leaning on his cane, smiling into the camera. If he can be so beautiful standing on that treelined walkway, maybe I can be too. I want to grow to a place where I can fill my skin to its very edges. For any of us to do this work, we need all the allies, lovers, community, and friends we can gather, all the rabble-rousing and legislation, all the vibrant culture and articulate theory we can bring into being.

+ + +

In the end, I am asking that we pay attention to our bodies—our stolen bodies and our reclaimed bodies. To the wisdom that tells us the causes of the injustice we face lie outside our bodies, and also to the profound relationships our bodies have to that injustice, to the ways our identities are inextricably linked to our bodies. We need to do this because there are disability activists so busy defining disability as an external social condition that they neglect the daily realities of our bodies: the reality of living with chronic pain; the reality of needing personal attendants to help us pee and shit (and of being at once grateful for those PAs and deeply regretting our lack of privacy); the reality of disliking the very adaptive equipment that makes our day-to-day lives possible. We need to do this because there are disability thinkers who can talk all day about the body as metaphor and symbol but never mention flesh and blood, bone and tendon never even acknowledge their own bodies. We need to do this because without our bodies, without the lived bodily experience of identity and oppression, we won't truly be able to refigure the world, turning it to a place where, to quote the poet Mary Oliver:

... each life [is] a flower, as common as a field daisy, and as singular,

and each name a comfortable music in the mouth, tending, as all music does, toward silence,

and each body a lion of courage, and something precious to the earth. $^{1}\,$

Eli Clare is a poet, essayist, and activist living in Michigan. She is the author of *Exile and Pride: Disability, Queerness, and Liberation* (1999).

1. Mary Oliver, New and Selected Poems (Boston: Beacon, 1992), 10.