

Staring Back: Self-Representations of Disabled Performance Artists

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THE MEANING OF THE BODY, THUS THE MEANING OF THE SELF, EMERGES through social relations. We learn who we are by the responses we elicit from others. In social relations, disabled bodies prompt the question, "What happened to you?" The disabled body demands a narrative, requires an apologia that accounts for its difference from unexceptional bodies. In this sense, disability identity is constituted by the story of why my body is different from your body. Disability autobiography is a recently burgeoning form of textual self-representation that centers on answering the urgent question "What happened to you?" through narrative. All forms of self-representation are inherently relational in that they presume that the representation one creates will be apprehended by someone else.

Disability performance art is a genre of self-representation, a form of autobiography, that merges the visual with the narrative. As a fusion of both seeing and telling, disability performance art foregrounds the body as an object both to be viewed and to be explained. The disabled body is not only the medium but the content of performance. The disabled body on view *is* the performance. Rather than only telling the required disability story, then, disability performance acts out that story. In addition to always addressing the question of "What happened to you?" that textual autobiography answers, disability performance at the same time reenacts the primal scene of disability in which the normative viewer encounters the disabled body and demands an explanation. Simply the presence of the visibly disabled performer on stage engenders this dynamic between the performer and her audience.

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By presenting her body before a viewer, the visibly disabled performance artist generates the dynamic of staring, the arrested attentiveness that registers difference on the part of the viewer. In the social context of an ablist society, the disabled body summons the stare, and the stare mandates the story. The stare, in other words, evokes the question, "What happened to you?" This stare-and-tell ritual constitutes disability identity in the social realm. This exchange between starer and object registers both the anonymity that confers agency on the starer and the singularity that stigmatizes the one who is stared at. Staring is thus the ritual social enactment of exclusion from an imagined community of the fully human. This relational model suggests that disability is not simply a natural state of bodily inferiority and inadequacy. Rather, disability is a culturally fabricated narrative of the body, similar to what we understand as the fictions of race and gender.³

Why would a person with a visible disability, someone with a body that disrupts the expectations of the complacently normal, deliberately invite the stare-and-tell dynamic that constitutes her otherness? A survey of disability performance art suggests that such performances are platforms for profoundly liberating assertions and representations of the self in which the artist controls the terms of the encounter.⁴ In addition to allowing individual expression, this artistic engagement with self-display also provides a medium for positive identity politics and an opportunity to protest cultural images of disabled people. Disabled performance artists manipulate the stare-and-tell dynamic. I would argue, in fact, that disability performance art is a genre of autobiography particularly appropriate to representing the social experience of disability precisely because it allows for creating both visual and narrative self-representations simultaneously and because it traffics in the two realms of representation fundamental to the social construction of disability identity.

One of the most compelling examples of the liberatory potential of disability performance is Mary Duffy, an Irishwoman who appears extensively before U.S. viewers. Duffy, who is armless, with a delicate hand attached directly to one shoulder, always presents herself nude in performances. A "severely disabled" woman by the standards of what disability historian Paul Longmore calls with great irony the "severely able-bodied," Duffy boldly exposes the body that has always been hidden, both shocking and compelling her viewers.⁵ Her performances begin with a totally darkened room that wipes away all ocular options,

clearing the audience's visual palate. For an almost uncomfortable period of time, the viewers see nothing. Amid the darkness, a series of enigmatic black and white images seem to float up; they are piles of smooth stones that increase in number as each image changes to the next. During this prolegomenon, this critical introduction, the clusters of stones grow and the sound of a chugging train that transforms into a beating heart begins to accompany the images. The suggestion of embryonic development and fetal heartbeat becomes clear. Then out of the darkness the form of Mary Duffy suddenly appears, spotlit from the front and against a black background. The scene dramatically obliterates all visual alternatives except Duffy's ultra-white form, forcing the audience to look at her completely naked body, posed as the classical nude figure of the Venus de Milo, the quintessential icon of female beauty. Young, full-breasted, voluptuous, beautiful, and armless, this living Venus demands with her silent presence that the audience stare at her. This arresting choreography hyperbolically, almost parodically, stages the dynamic of two opposing modes of looking: staring at the freakishly different body and gazing at the female body as a beautiful work of art.

The viewer becomes the starer trained by the social order to see Duffy's body as a pathological lack, a deviation from the norm that has either been hidden away in the asylum or displayed in medical photographs with a black bar over the eyes to obliterate personhood. Hers is the sensationally abnormal body glimpsed furtively in the tabloids and yet proscribed as an object of proper bourgeois looking. Like gawking at a fatal traffic accident or the primal scene, looking at Duffy is at once compelling and illicit. But Duffy's body also evokes the familiar contours of beauty. Duffy's simultaneously starkly disabled and classically beautiful body elicits a confusing combination of the rapt gaze and the intrusive stare. The literally in-your-face white figure against the black background is at once the degraded and the exalted body in the western tradition of looking. The templates culture has supplied her audience are inadequate to make sense of her body. Framed as a work of art, her body is paradox incarnate, leaving her viewers' sense of the order of things in ruins. Hers is the art that transforms consciousness, that grants a new way of seeing the known world.

Having manipulated staring to upset any simple notion of disability identity, Duffy moves into the narrative part of her performance, answering the ritualistic question that her exposed body elicits: "What happened to you?" Shifting the classical allusion from Venus de Milo to Pygmalion, Duffy begins to speak:

You have words to describe me that I find frightening. Every time I hear them they're whispered or screamed silently, wordlessly through front to middle page spreads of newspapers. Only you dare to speak them out loud. I look for them in my dictionary and I only find some. The words you use to describe me are: "congenital malformation." In my child's dictionary I learn that the first part means "born with." How many times have I answered that question, "Were you born like that or did your mother take them dreadful tablets?" How come I always felt ashamed when answering those big staring eyes and gaping mouths? "Did you have an accident or did your mother take them dreadful tablets?" Those big words those doctors used—they didn't have any that fitted me properly. I felt, even in the face of such opposition, that my body was the way it was supposed to be. It was right for me, as well as being whole, complete and functional.

Unlike Pygmalion, however, Duffy does not affirm the perspective of her creator when she turns from silent object of the stare into a speaking subject. The words she cites are the verbal equivalents of the stare she sets up between herself and the audience. Yet, in this narrative, the words come from her own voice in performance rather than from the array of starers she has faced during her lifetime. By appropriating the words others use to describe her body, she upsets the dynamic of the stare, repeating in a kind of testimony the words of her starers while forcing the audience to look at a classic image of female beauty bearing witness to its own enfreakment by those words. Duffy's telling of her life flings the words, the questions, and the stares back at her lookers, rebuking the aggregate "you" who cast her as pathological specimen, freak of nature, or quintessential lack. She accuses them with their own accusing questions to her about being "born like that." She stares out at them, upbraiding them for their intrusive "staring eyes and gaping mouths" that made her feel "ashamed." Dismissing their perceptions of her body, she insists upon her own self-definition, asserting that "words" such as "congenital malformation" do not accurately describe her experience of herself. Her soliloquy moves from exorcising the oppressive language that defines her to voicing her own version of herself as "being whole, complete and functional."

By manipulating the stare-and-tell ritual so fundamental to disability experience, Duffy mounts a critique of the politics of appearance and an inquiry into what it means to be an embodied person. Her selfrepresentation raises the issue of what is appropriate looking, queries what constitutes beauty, and asks what is the truth of the body. This autobiographical form unsettles cultural assumptions about humanity, femaleness, disability, and self by invoking and juxtaposing all of these categories. By merging the visual and the narrative, body and word signify together in an act of self-making. Unique to disability, this genre manipulates the stare in order to renarrate disability. The body is integral to the word, operating as a material signifier that generates the stare-and-tell dynamic. By appropriating the social practice that constitutes her oppression in order to reimagine her identity, Duffy enacts a kind of communal renunciation of the objectification that she so commandingly rejects in her performances. In creating such an art form, she boldly reimagines disability on behalf of her community: other disabled people for whom the daily business of life is managing, deflecting, resisting, or renouncing that stare.

NOTES

- 1. Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, N.J.: Prentice Hall, 1963).
- 2. G. Thomas Couser, *Recovering Bodies: Illness, Disability and Life Writing* (Madison, Wisc.: Univ. of Wisconsin Press, 1997).
- 3. This is not to suggest that disability has no lived, corporeal reality. Indeed, disabled subjectivity is determined in part by the experience of impairment and of a disjuncture between an ablist physical environment and the disabled body. Here, however, I want to focus on the social exchange of staring as a cultural context that constitutes disabled identity.
- 4. Other disabled performance artists include Cheryl Marie Wade, David Roche, Billie Golfus, Carrie Sandoval, and Bob Flanagan; on Flanagan, see Linda Kauffmann, *Bad Girls and Sick Boys* (Berkeley, Calif.: Univ. of California Press, 1998). Several performers appear in the film *Vital Signs: Crip Culture Talks Back*, directed and produced by David T. Mitchell and Sharon Snyder (Marquette, Mich.: Northern Michigan Univ. distributor, 1996).
 - 5. Personal conversation with author, 20 June 1997 at Washington, D.C.
 - 6. Vital Signs: Crip Culture Talks Back.
- 7. "Enfreakment" is a term coined by David Hevey, *Creatures Time Forgot: Photography and Disability Imagery* (New York: Routledge, 1992).