

BOOK REVIEW

Narrative Practices of Disability Beyond Its Representation

Michael Bérubé. The Secret Life of Stories: From Don Quixote to Harry Potter, How Understanding Intellectual Disability Transforms the Way We Read. New York University Press, 2016. Hardcover ISBN 978-1-4798-2361-1.

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A significant issue in Michael Bérubé's new book is what happens when a protagonist is not capable of understanding the narrative that she or he is in. Part of the pleasure of reading Bérubé is the firmness of his own grasp on the kind of narrative he is writing, and a complex critical narrative it is. Bérubé likes to mix genres; his earlier books mix disability studies, educational policy, literary criticism, and memoir. His 1996 book, *Life as We Know It*, begins with the birth of his younger son, Jamie, who has Down's syndrome, and moves outward to advocate for classroom mainstreaming, by way of considerable discussion of Michel Foucault. The present book picks up Jamie's story, but now Bérubé's concern is literary criticism itself, within disability studies.

At the end of *Secret Life*, Bérubé is clearest about what he has been writing. On the one hand, the book "is a work of literary criticism, meant to continue and expand a conversation among a small group of specialists who practice the arts of advanced literacy" (p. 192). Those considering whether to read this book should take that statement seriously. Bérubé's style here is academic, in that most of the book comprises either debates with other disability scholars or close readings of texts. These include *Don Quixote* (Cervantes, 1605/2003) and *Harry Potter* (Rowling, 1999) as the subtitle promises, but more time is spent on Faulkner's (1929/1991) *The Sound and the Fury*, Nabokov's (1962) *Pale Fire*, and Philip K. Dick's (1964/2012) *Martian Time-Slip*. Bérubé

expects his readers to already know these books, with the exception of *Martian Time-Slip*, which he acknowledges will be known only by readers who are "level-six PKD fans." As Bérubé then lays out that book's plot, I realize that I'm not even at level one. The point is, this book is by a specialist, for specialists.

Yet Bérubé is just too broad-minded, and too socially concerned, to write only for those who will use his book as fodder for symposia at academic conferences, which it deserves to be. One of his main interlocutors is the disability scholar Ato Quayson (2007), whom he quotes giving a lecture in his native Ghana. Quayson asks what the relationship is between his own academic work that engages level-six literary texts and what he neatly calls "the condition of the lives of disabled persons on the streets where I grew up" (Bérubé, p. 193). In Bérubé's words, "the stakes are ultimately about who is and who is not determined to be 'fully human,' and what is to be done with those who (purportedly) fail to meet the prevailing performance criteria for being human" (p. 192). Even when Bérubé is at his most academic, there is always an undercurrent of social justice issues that affect disabled persons living on streets where these books have little presence.

One limit of this review is that I am not among the "small group of specialists" to whom the arguments are primarily directed. Nor did *Secret Life* make me want to take up any of the books he discusses. My question is whether Bérubé delivers on the promise at the end of his subtitle: does *Secret Life* transform the way we read not only literary works but all manner of texts, including the sort of personal narratives given voice in social science interviews, in medical consultations, and in therapy sessions? I believe it does. To say why, I apologize that simplifying the literary-critical issues seems a cost of shifting the "lives ... on the streets" from the book's background and treating them as the foreground. Fortunately, this book will not lack intensive review in other journals by literary critics who will give that aspect due consideration.

Bérubé's collegial quarrel is with disability scholars whose main concern is diagnostic, in sense of focusing on "whether X character has Y disability" (p. 15) and then questioning the accuracy of the representation of that disability. He is concerned that literary disability studies as a field not be "confined to the representation of human bodies and minds in literary texts" (p. 25). "I am determined to cure disability studies of its habit of diagnosing fictional characters" (p. 20; cf. p. 128), he writes. Those of us not working in disability studies might well pause over that statement and ask how we also have succumbed to "the temptation to

think that a diagnosis 'solves' the text somehow" (p. 20). I see that temptation in the thematic-analysis articles that fill health research journals. When the narratives that participants have offered in interviews are reduced to six or eight themes produced by the analysis, these themes can be presented as a diagnosis that somehow solves the category of person being studied.

What Bérubé does want to ask is how disability works in the narration itself, including how narration can become disabled. Here we return to the issue with which I began this review. Bérubé's interest is in "gauging how literary works depict systems of sociality in part by including characters who either are or are presumed by their fellow characters to be constitutively incapable of understanding or abiding the social systems by which their worlds operate" (p. 21). I would call that interest pre-eminently sociological. The big game for Bérubé is the "very possibility of narrative representation" (p. 64). Social scientists too often either understand their own representations to be guaranteed by canonical methods of analysis, or else they accuse others' representations of being products of ideology: that is, as being slanted according to group interest of those who have power to represent. If these reductionisms of method and ideology as solutions to problems of representation are complementary to Bérubé's reductionism of diagnosis, then his critique has a more general significance.

How, shifting from critique to the affirmative argument, is narration itself to be the object of analysis? Bérubé realizes that he can better show the sort of criticism he advocates than he can describe it, and he will frustrate readers looking for programmatic steps of critical reading. One can hardly be more anti-programmatic, or anti-method, than Bérubé's "radically Heraclitean understanding of disability and narrative, whereby we can never step into the same interpretive river twice The next time you encounter [fictional characters], they will be slightly different, and so will you" (p. 50). Few statements could cause more discomfort in some quarters of qualitative health and other social scientific research. But, I would add, if the characters will always be different, the cultural and institutional systems out of which these characters fabricate meaning and possibilities of action will have some consistency.

If Bérubé makes a principled refusal of method, at least the parameters of his critical activity are expressed in the titles of the book's three chapters: *Motive*, *Time*, and *Self-Awareness*. By *motive*, he means not the motivation of individual characters, but rather "the condition of

possibility for the text and its apprehension by readers" (p. 72). It matters less to Bérubé whether some characters have specified disabilities. The scope of disability studies' interest should expand to modes of narration that call attention to problems of their own possibility and apprehension. In *Don Quixote*, the characters come upon and react to a book already written about the adventures they have just had. In my words, their story becomes another character affecting the story they are currently living. In *Martian Time-Slip*, time keeps folding back, so later events disrupt, or seek to disrupt, the conditions of possibility that led to these events. When I found this realm of metafiction too far removed from "lives ... on the street," I had to ask myself if I was simplifying the issues of narrating those street-level lives.

The simplest gloss of Bérubé's message for those of us who are not literary critics is that in our narrative analyses, we need "to stop ourselves from reading right past the text to the 'content' within" (p. 135), as if that content could be abstracted from the narrative practices of its expression. At least one more complex lesson is suggested when Bérubé writes that as *Pale Fire* is narrated, "we simply cannot determine what we need to believe in order to join the narrative audience" (p. 149). By *narrative audience* he means the audience of "hypothetical people who believe everything a narrator tells them" (p. 148). The analytic objective is not to join this audience oneself, but rather to specify the conditions for joining it, and to explore who finds it impossible to join that audience. The focus shifts away from specific differences that make specific people different. Bérubé's interest is differences in narrational modes that make possible understanding otherness itself.

I do not pretend to understand Bérubé fully, only well enough to claim that he does transform the way I read. He enables me to better articulate why I find some narrative analyses reductive, and he shows me possibilities—albeit virtuosic in his exemplary readings—for being in a different relation to narrative.

References

Bérubé, M. (1996). *Life as we know it: A father, a family, and an exceptional child.* New York, NY: Pantheon.

Cervantes. (2003). *Don Quixote*. (E. Grossman, Trans.) New York, NY: HarperCollins. (Original work published 1605)

Dick, P. K. (2012). *Martian time-slip*. Boston, MA: Houghton Mifflin (Mariner). (Original work published 1964)

Faulkner, W. (1991). *The sound and the fury*. New York, NY: Vintage. (Original work published 1929)

Nabokov, V. (1962). Pale fire. New York, NY: Putnam.

Quayson, A. (2007). *Aesthetic nervousness: Disability and the crisis of representation*. New York, NY: Columbia University Press.

Rowling, J. K. (1999). *Harry Potter and the philosopher's stone*. London, England: Bloomsbury.

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