

Disability and Autobiography: Enabling Discourse

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As a student of autobiography, I have been drawn to the study of disability by the apparent openness of the genre to the experience of disability and by a number of recent works taking advantage of the medium's accessibility. For me, then, the crux of the study of autobiography and disability has to do with matters of mediation: the complex relation between the conventions of autobiographical writing and the experience of disability. (1)

In light of the typically negative portrayal of people with disabilities in various media, most notably fiction and film (2), the appeal of autobiography is that it is, by definition, self-representation. Therein lies its liberatory potential; as self-representation, autobiography is perhaps uniquely suited to validate the experience of people with disabilities and to counter stereotypical (mis)representation. Moreover, insofar as autobiography is the literary expression of the self-determined life, the genre that may be said to embody personal autonomy, it seems an ideal medium for contesting the association of disability with dependence and invalidity. Writing autobiography, preferably without assistance, may enable individuals with disabilities to cross back over the border into the mainstream or, better yet, to cross out that border.

On the other hand, although it may be the most democratic of literary genres, autobiography, like other presumably accessible institutions, effectively excludes some people with disabilities. For one thing, severe impairments may impede or prevent individuals from writing their own lives; the process of composition may simply be too arduous. Even when impairment is not an insurmountable obstacle to writing, the literary/cultural marketplace operates in such a way as to shape the genre in ways that may discourage life writing by people with disabilities. One often overlooked expectation of autobiographical narrative is that it will have a comic plot: the protagonist of an autobiography is typically better off at the end of the story than at the beginning. If chronic physical disability - for example, paralysis - is perceived as stasis, it may seem incompatible with plot of any type - and thus seem unnarratable.

The convention of the comic master plot tends to discourage personal narrative by those whose life trajectories do not correspond to traditional patterns of individual development.

Historically, access to autobiography has required preexisting distinction - success or celebrity - and those have been parcelled out unequally. Serious disability, especially if it is incurred early in life, may obstruct or preclude "normal" life -

work or career, marriage or partnership, bearing and raising children - let alone the sorts of distinction that autobiography has traditionally demanded. The situation of individuals with disabilities is that their most obvious "distinction" is one that may disqualify them as autobiographers, unless it can somehow be made the focus for the book, the hook for the reader. But if the disability becomes the whole subject of the story, there is some risk of reducing autobiography to case study - reifying disability and thus reinforcing marginalization. In addition, the cultural values of autonomy and independence that autobiography celebrates are not entirely sympathetic to people with disabilities; to some, they are unattainable, hence inappropriate, ideals.

What the literary marketplace seems to demand of disability autobiography, then, is the story of triumph over tragedy, which reinforces rather than questions the popular conception of disability as a character-testing catastrophe. In order to justify writing their lives, people with disabilities, whose lives are generally devalued, may have to represent themselves as so exceptional as to be misleading examples - "supercrips." (This is true to some extent of John Hockenberry's *Moving Violations* [1995].) So, while autobiography may seem inherently amenable to the positive representation of people with disabilities, cultural expectations may work to minimize its liberatory potential. We are left with the paradox that those individuals with disabilities who represent themselves in autobiography may not in fact be very representative - i.e., typical - of those with disabilities.

Nor will various impairments be represented in proportion to their numbers. For different reasons, disability is most frequently represented in the form of manifest physical disability, especially paralysis. Paralysis bids to become the paradigmatic form of physical disability partly because of its obviousness, extremity, and apparent intractability. In addition, gender plays a considerable role. In view of the fact that disabled women outnumber disabled men, the prominence of published narratives of male paralysis says much about the gendering of disability. One of the common gender patterns in disability is the paralysis of young men from injuries in high-risk activities - like war and violent sports. These sudden accidental disabilities incurred by virile young men - soldiers and athletes - get more than their share of media attention. (3)

The use of a wheelchair literally lowers a person's stature (and implicitly status), and the apparent uselessness of the lower body implies a lack of potency, sexual and otherwise (whereas in fact male and female paraplegics are quite capable of having children). In a patriarchal culture, these deficits may be considered more costly, more tragic, when incurred by men (and thus more heroic when overcome by them). The prominence of male accounts of paralysis, then, may have much to do with the association of paralysis with emasculation, even feminization.

The story of the disabled male is privileged because of the semiotic clash

between the modifier and the noun, whereas the story of the disabled woman may be ignored because of its apparent redundancy. When impairment deprives someone of the appearance of autonomy and potency, that person's story is unwriteable and unreadable unless and until he or she can claim some compensatory power and freedom. Because it may so dramatically threaten one's sense of integrity and may so radically rupture one's sense of autobiographical continuity (especially when it is the result of accident or illness in adult life), paralysis seems to call for compensatory or therapeutic narration. In a patriarchy, of course, such compensations are more available to men than to women. This helps to explain some of the lack of diversity in those who have narrated their physical disability. While those who work with their minds are generally more likely to write autobiography than those who work with their bodies, this may be especially so among people with disabilities, for the vocation - and thus the self-respect - of professionals is more likely to survive their disability. In any case, the authors of the narratives I have investigated so far are not very "diverse" in race, gender, or class; they are mostly white male professionals. As such, they were well positioned to become or remain economically viable in spite of their impairment; their intellectual power serves to compensate for their loss of physical power and control of their lower bodies.

One of the significant patterns in their accounts is the redemptive shifting of emphasis from the body to the mind. Self-rehabilitation involves, in large part, redefining the self as more a function of mind and spirit than of the flesh. (Which is to say that it reinforces the cultural identification of men with the mind, women with the body, and the privileging of the former over the latter.) Hence the powerful appeal of the conversion paradigm. But while the paradigm of conversion may operate to reinforce the stigma of disability - as I believe it does in Oliver Sacks's *A Leg to Stand On* (1984), where recovery from temporary paralysis is explicitly associated with a mysterious infusion of grace - it may be used more counterdiscursively - as in Leonard Kriegel's *Falling Into Life* (1991) and Reynolds Price's *A Whole New Life* (1994). Kriegel subtly and self-consciously detaches the notion of falling from its biblical connotations, stressing instead its literal role in his rehabilitation from polio. Similarly, Price separates his sense of spiritual assurance from his bodily condition, which stabilizes but does not improve. The effect of both is to demystify disability.

The most promising pattern in disability autobiography, however, is the emergence of the "autoethnography," exemplified by Robert Murphy's *The Body Silent* (1987) and Irving Zola's *Missing Pieces* (1982). These narratives explicitly embrace the social or "minority model," in which disability is less a matter of individual anatomical dysfunction than of prejudice defining whole groups of people. Such a paradigm removes the onus from the individual and suggests the potential

for oppositional cultural work and for pride in one's identity.

I want to emphasize the provisional and preliminary nature of my research so far, which has focused on a fairly narrow selection of texts and only two conditions, deafness and paralysis. Recently, I have begun to look more closely at "limit cases" such as *I Raise My Eyes to Say Yes*, by Ruth Sienkiewicz-Mercer and Steven B. Kaplan (1989), and *The Diving Bell and the Butterfly*, by Jean-Dominique Bauby (1997) - narratives produced by people with impairments so severe as to seem to preclude autobiography entirely, and I hope to broaden my inquiries into other collaboratively produced narratives that, partly for that reason, contest the cultural ideals of autonomy and independence. (Collaborative autobiography has been somewhat suspect in the academy, but recent developments in feminism and poststructuralism and the recognition of the inherent relationality of subjectivity and narrative have encouraged the reexamination and rehabilitation of such texts.)

In conclusion, I should point out that, as with other minority movements, we can expect the ongoing development of political consciousness among people with disabilities to result in an increase in the quantity, and a change in the conventions, of narratives of disability. Disability narrative is still, I think, in the early stages of development as a self-conscious and counter-discursive form of life writing.

Notes

1. My book, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: University of Wisconsin Press, 1997) has a chapter on autobiographies by people with disability in the form of paralysis and one on personal narratives (primarily not autobiographical) of deafness. Because the two conditions raise very different issues, and because of limitations of space, I confine my comments here to narratives of physical disability.

2. I trust there's no need to rehearse here the list of deformed or otherwise mutilated villains and grotesques in our literary tradition, which Paul Longmore, Leonard Kriegel, and others have delineated.

3. Although he is no longer young, the identification of Christopher Reeve with the role of Superman makes his case a particularly significant example of this phenomenon. Random House has promised him a \$3,000,000 advance for an account of his recovery; it will be interesting to see what form his proposed autobiography will take (Gabriel A5).

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