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Review Essay

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## Method and Substance in Sociological Studies of Disability

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**Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America.** By Frank, Gelya. Berkeley: University of California Press, 2000. 284 pages, paperback, ISBN: 0-520-21716-0.

**Meaning of a Disability: The Lived Experience of Paralysis.** By Robillard, Albert R. Philadelphia: Temple University Press, 1999. 191 pages, paperback, ISBN: 1-56639-676-X.

**Mixed Connections: Hard of Hearing in a Hearing World.** By Stenross, Barbara. Philadelphia: Temple University Press, 1999. 139 pages, paperback, ISBN: 1-56639-682-4.

These three books each deal with the lived experience of disability. One (Robillard's) is written by and about the person who experiences the disability (total paralysis, including the ability to produce speech), but the other two authors also have some intimate connection with the world of the disabled. Stenross herself has some hearing loss, and her father was hard of hearing in the way of those who occupy the pages of her book, but the majority of her book is about the lives of her research subjects. Frank does not have any physical disability, but she is a close friend of the person who is disabled (born with no arms or legs). Thus, two of the books are biographical (one autobiographical) and the other a more traditional ethnography.

One common element of these books, apart from their focus on disability, is that they contain relatively little explicit use of sociological concepts. Robillard and Stenross mention sociology only occasionally, and Frank relegates most of her sociology/anthropology to the endnotes (fifty-eight pages, almost one-quarter of the text, but hidden away from the readers such that they must seek them out rather than presenting them as footnotes). While I can appreciate the potential of this

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strategy to increase sales to nonacademic audiences, I deplore the lost opportunity to show these same audiences how social science contributes to our understanding of the world around us. Frank does the best job here, with a running commentary explaining how her work relates to other social science ways of knowing. She articulates the epistemology of biographical accounts in a way that Robillard does not. Perhaps this is a result of the fact that she was trained in this social science methodology whereas Robillard, an ethnomethodologist, was not.

I found it interesting that ethnomethodology, a relatively small part of the discipline of sociology, occupied a relatively significant position in these works. Frank thanks two ethnomethodologists in her personal acknowledgments and Stenross cites the work of two other ethnomethodologists. Robillard trained with the founder of ethnomethodology, Harold Garfinkel, and sees this discipline as central to his perspective on his paralysis. There are several ironies for Robillard and ethnomethodology. Robillard explains that to a large degree he left ethnomethodology behind as he went on to develop a distinguished career in medical sociology. It was only when he sought to understand his later experience of paralysis that he returned as a prodigal son to his disciplinary roots. Another irony involves the relationship between his early work in the field and his current work. His dissertation was an exceptionally demanding theoretical exegesis on Hegelian hermeneutics, the current work a very accessible concrete account of his own embodied experiences. At a deeper level I sensed fundamental commonality between the two works, but not one I can articulate. I wish Robillard had devoted more of his effort to this task, but he does note how ethnomethodology's "unique adequacy requirement" shaped his self-study. In order to meet this requirement, other students of Garfinkel have trained to become practitioners of legal (Stacy Burns) and mathematical (Eric Livingston) work so they could understand this work as practitioners do. While Robillard did not choose to become a participant in the topic of his study, he has taken advantage of his learned expertise.

Perhaps a fairer criterion for assessing the sociology in these books is to consider both implicit and explicit elements. Here the works receive better marks. For example, Robillard not only deals with his difficulties in managing day-to-day physical tasks, but also focuses on social interactions. Indeed, in the spirit of some early work in ethnomethodology, he sees his own paralysis as a condition which exposes a variety of taken-for-granted features of our everyday social arrangements. For example, we learn not only how difficult it is to move when one must rely on others to position one's wheelchair, we also learn how dependent social interaction is on the physical positioning of co-interactants vis-à-vis one another, and the ability to produce text in real time. Without these abilities Robillard is often reduced to being an observer rather than a participant in interaction, one of the major hardships resulting from his condition. However, disembodied forms of social interaction (e.g., e-mail) allow him to maintain participation in social

networks beyond that of the intimate circle of those who have been able to adapt to his idiosyncratic communication practices.

Frank's book involves a personal account on two levels: as a biography of a disabled person (Diane), and as an autobiography of the author's life and relationship with that disabled person. This work is clearly in the tradition of the "new" ethnography in which the personal experience of the author becomes the defining element of the world to be studied. We see the life of a disabled person as manifested in the relationship with a nondisabled person who is an authorized biographer. Much of the book is self-reflective and explicitly considers how the nature of this relationship illuminates both the nature of what it is to be disabled, and how the account of that experience is influenced by the relationship within which the account is constructed. Frank alternates between discussing the "facts" of Diane's life, her interaction with Diane, and her thoughts about Diane. The subject-biographer relationship comprises the fourth theme, explicit consideration of which forces/allows the reader to take into account the way that the research process shapes the subject matter represented in the other three themes.

One interesting feature of this book may escape the reader who is not attuned to it. The book discusses numerous problems in living, some of which are tied to the disability (e.g., discrimination), others not (e.g., marital problems). While this could be seen as a flaw in the book (i.e., it does not concentrate on disability), in fact it conveys an important message—disability is only one part of the lives of the disabled. Disability may be a master status that colors everything about a person, but it does not determine how Diane lives as a disabled person. Diane addresses this issue explicitly at times, and allows us access to her life to perform our own examination.

Finally, the book by Stenross is at once both the most and least sociological. It is the most sociological in that it uses a traditional sociological methodology consisting of participant observation in a self-help group for persons living with hearing loss (those who have the condition and those who live with them). I say participant observation rather than observation because Stenross has a personal involvement with hearing loss which enters the work, but only at selected points (unlike its central place in Frank's work). Yet it is perhaps the least sociological in its self-avowed intent to serve a self-help purpose. Much of the book is concerned with practical advice on how to manage hearing loss—from the hearing-assistive devices available and how to choose and use them to how to cope with hearing loss. The most sociological topic of the book echoes that of Robillard—how social interaction is influenced by the disability. Stenross provides a variety of tips on how to manage this difficulty. Her approach results in a book which may be more interesting to persons who live with hearing loss than to sociologists.

How might these books be used by sociologists? Methodologically, each represents a distinct type of qualitative/ethnographic approach which might be used to provide exemplars to a beginning graduate student in a qualitative methods course.

Of course, these books would need to be supplemented with more traditional exemplars as well, e.g., Whyte's community ethnography *Street Corner Society*, which provides insight into multiple life stories (combining the biographical focus of Frank and Robillard with the multiperspectival focus of Stenross), Anderson's traditional community ethnography *Code of the Street*, and organizational ethnographies such as Goffman's *Asylums*.

For the sociologist of disability, these books are most effective in illuminating the difficulties in communication between disabled and nondisabled persons. For Robillard and Stenross these difficulties start with communication disabilities, while for Frank the difficulties are more a function of what people think about a person who has a noncommunicative disability. In all three books we see the efforts of the disabled to overcome their disabilities. Some of these efforts are heroic, others mundane, but all represent the fundamental human spirit. Students and professionals (in sociology or not) can learn about what it means to *live* as a disabled person by reading these books. These books teach us not only about the microstatus of the disabled—the positions into which society places them—but also about their role dynamics—how they construct the worlds in which they live.