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BOOK REVIEW

FEMALE FORMS: EXPERIENCING AND UNDERSTANDING DISABILITY

by *Carol Thomas*

Reviewed by **Robin Smith**

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Female Forms: Experiencing and Understanding Disability. By Carol Thomas. (1999). Philadelphia: Open University Press. 175 pages. ISBN 0335196934

When I began to participate in the early '80s national and local fight for wheelchair accessible mass transit, people with disabilities were fighting the medical model and telethon images in the streets, hearing rooms and boardrooms. The political was indeed personal. The most common phrase heard at a 1986 "Disabled women's Speakout" in Syracuse, New York was, "We are human beings." Not only could we not get jobs, we could not even get to work. Potential dates and mates for wheelchair users fled at parties, and our actual mates were declared "saints" by our non-disabled peers. Disabled women earned considerably less than 66 cents to a dollar. "Sexism Without the Pedestal" (Fine 1993; Fine & Asch 1981) was the

first and, for a while, the only article in print that acknowledged our oppression to a wider community and introduced our existence to the women's movement. This was followed closely by the Women and Disability edition of *Off Our Backs* (1981), finally beginning the intersection of disability activism and the women's movement. In fact, my literature review for a paper on the topic 10 years later yielded nothing but medical articles before 1980. The intersection turned out to be a rocky road to alliance building because of differences and conflicts over abortion, choice, prenatal screening (pro-choice and anti-choice advocates seemed to agree on one point—it was alright to abort a disabled baby), and approaches to organizing. The working definition of disability for U.S. advocates at the time was taken from the Rehabilitation Act of 1973 that prohibited discrimination in federally funded organizations against "otherwise quali-

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fied handicapped individuals." The regulations, and later the Americans with Disabilities Act, defined disability as an impairment that "substantially limits one or more major life activities." Both laws also applied to those who were perceived to have an impairment. For us, non-academics in the street, that took care of our social model of disability. We were ready to fight institutional and attitudinal oppression and its internalized forms. And so when several years later (late 90s) as an academic I discovered oppression and internalized oppression actually written about in Disability Studies I could not help remembering the tensions between the personal and political and the "malestream" and feminist approaches to our political and social advocacy. And so it was with great interest that I read Carol Thomas's new book, *Female Forms: Experiencing and Understanding Disability* (1999). This is an ambitious and well-crafted book outlining the history of British Disability Studies and its relation to feminism in order to promote theoretical development of the social model of disability in relation to feminist ideas and medical sociology.

Female Forms is laid out in three parts. Part 1 defines disability. Part II, "Female Forms," takes on the issues of personal and political, gender, and feminist approaches to disability, impairment, and difference. Part III, "Understanding Disability," moves the reader toward a theory of disability and impairment and includes the dilemmas and contributions of medical sociology. Each chapter ends with a discussion clarifying what Thomas sees as the key theoretical question, "How are the social relationships which constitute disability generated and sustained within social and cultural formations?" (p. 3)

Part I, "Defining Disability" traces the development of the social model of disability and the emergence of Disability Studies. Chapters 1-3 debrief the history of the social relational model of disability. The narrative includes several definitions. The following for the social model of disability is representative: "Disability is redefined as the outcome of

social arrangements and practices which work to exclude and disadvantage people with impairment; social barriers place restrictions on what they can do and how they can live. In this way disability becomes a new form of oppression." (p. 1) Here Thomas proceeds to introduce critiques of the social model including the gendered nature of this model.

Chapter 1 narrates the history of the social model of disability and the history of disability studies. The social model of disability introduced to the public a new form of oppression and scholars like Oliver (1996, 22) made a distinction between impairment ("lacking all or part of a limb, or having a defective limb, organ or mechanism of the body") and disability ("the disadvantage or restriction of activity caused by a contemporary or social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities"). This model succeeded as a major departure from the medical model of disability. Thomas, then, continues with the evolution of social definitions of disability.

Forewarning the reader that she will argue with this definition of disability, Thomas punctuates the evolving social definitions with quotes from an extensive collection of written and interview materials. She culled these from among 80 responses to a request to be in her study of personal experiences of women with disability. In fact 49 sent her written interviews and another five sent self-recorded tapes.

She thus supplies the personal experiences of oppression that were missing from the social model. A woman who with a spinal injury at age 19 moved out on her own after seven years described "coming to terms with" her disability and the disabling nature of the built environment. Another respondent walked with a limp remaining from polio at age 2. She endured comments at her publishing job ("But she's got a limp." [p. 19]) and while representing another publishing house at an exhibition heard, "[The publisher] must be hard up for staff if he has to employ cripples." Yet the social model definitions and oppressive expe-

riences do not explain disability, nor impairment, nor the roots of the social barriers, nor "the mechanisms at work in shaping disabled people's experience." (p. 26). It does not explain the social exclusion of people with impairments or even what constitutes impairment. The social model is not a social theory. Furthermore, women with disabilities published a wide range of work to make women's experiences visible and important. She notes "that the experience of disability is always gendered" (p. 28) as evidenced in her literature review and the accounts of each of her respondents. Both discussion of the social model and the dilemma of personal experience of disability are present but as yet unacknowledged by scholars (I really can't climb stairs in my wheelchair or read without my glasses no matter how liberating my fellow humans may be.)

Is disability only caused by social factors? Are impairments and chronic illnesses never disabling? Chapter 2 explores this definitional riddle:

Disability is about restrictions of activity which are socially caused. But some restrictions of activity are caused by illness and impairment. Thus some aspects of illness and impairment are disabling. But disability has nothing to do with impairment." (p. 39)

Her argument moves us to the next stage in redefining disability: it is a relationship. Impairments yield impairment effects:

...the restrictions of activities which are associated with being impaired but which are not disabilities in the social relational sense. Impairment effects may become the medium of disabilities in particular social relational contexts (p. 43).

My inability to climb stairs is an impairment effect. A public meeting called at an inaccessible site changes my stair climbing impairment effect into a disability. And yet, there are other effects to consider.

Disability and the social self (Chapter 3) must be accounted for. Disablism yields psy-

cho-emotional dimensions and we learn about them through personal narratives of painful rejections, abandonment, and the internalizing of society's images of the perfect body. One woman narrates a 50 year process of "coming to terms with having a disability" (pp. 50-51). Her accounts demonstrate the psycho emotional effects of living with sexist disablism in the workplace and the damage to self-esteem that comes with being treated differently and insensitively by parents. Thomas's examples demonstrate the close connection between the inner state and the way one is treated by non-disabled others. The social relational definition that Thomas finds most useful is further developed. The psycho-emotional dimension of disability (not to be confused with impairment effects) has been overlooked by many in Disability Studies. She concludes with this preferred definition taking into account the flaws of previous definitions:

A social relational definition of disability: Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being.(p. 60)

In Part II, Thompson turns to the further exploration of disability and gender, the personal and the political drawing on feminist perspectives. Chapter 4 discusses the place of "personal experience" in Disability Studies. She reviews the introduction of personal perspectives in Disability Studies by such authors as Jenny Morris (1991) who bring their personal perspectives into their research. Mike Oliver and others have argued against calls to account for personal experiences living with impairment. Thomas argues that "there are very sound reasons for taking the experiential seriously, including 'writing the self into one's analysis, reflexivity, and the utilization of what sociologists have termed 'autobiography.'"(p. 4). She demonstrates "unsustainable dualisms" in the work of those who invalidate personal experience, such as personal and political, pri-

vate and social. In the process she explicates the dilemmas involved in being indebted to feminists and feminist analysis that also excludes disability and the experience of disability and impairment. Disabled feminists writing themselves into their research began to influence such male writers as Tom Shakespeare or Mike Oliver who then called upon researchers to include their "intellectual biography" (p. 70) but stopped short of otherwise valuing personal plus relational perspectives by declaring "disablement has nothing to do with the body" (citing Oliver, p. 72). Refusing to separate private and personal from public and political, she includes respondent narratives that show the interlocking nature of these issues and concludes with the question,

What would be the consequences if the feminist position that all knowledge is 'situated' were taken seriously in Disability Studies? At the very least it would mean acknowledging that all knowledge about disability (and not just the knowledge of the medical modelists) is profoundly related to the conditions of its own production.... apparent social scientific truths about disability would be identified for what they are—'situated' attempts to interpret social reality which can be contested and debated. (p. 81)

Chapter 5 discusses in detail the gendered nature of disability. Thomas draws heavily on accounts of women narrating their day-to-day lives, showing how the experiences of disability are "refracted in some way through the prisms of gender locations and gender relations" (p. 4). She demonstrates that disability is gendered and complex. For example, one disabled woman was emotionally and physically abused by her disabled husband who refused to ask for help for himself. He also did not allow her to seek help after her impairment. Thomas then takes on the issue of multiple oppressions. She notes that the value of the writing about multiple oppressions after the Fine and Asch (1981) article was to put women with disabilities on the map. The problem with these images of disadvantage were that they

reinforced negative images of passive, oppressed women and obscured agency on the part of women who were disabled and also poor, black, lesbian, etc. Documenting protests against multiple oppression imagery by Morris and Wendell (1989, 1996) and by black feminist scholars Carby (1982) and Stuart (1993) who argue in favor of "simultaneous oppression" rather than multiple oppression, Thomas suggests that the experience of disability by people with other social identities is "more than the sum of its parts" (p. 98). Thomas asserts that she is trying to "illustrate difference in the context of sameness so that disabled women are not 'othered'" (p. 99); yet difference warrants deeper understanding.

Chapter 6 takes on a detailed inquiry of social difference. Thomas explains the differences between essentialist and constructionist approaches, touching on questions of identity politics and the debates on difference and identity. One dilemma she explores is "the paradox that by identifying and celebrating their 'difference' and division, women are reinforcing and sustaining distinctions which have been socially constructed within a male dominated society" (p. 103). While essentialism (outside and untainted by the patriarchal order) and constructionism (concerned with the production and organization of differences) appear to be opposites, Morris and Wendell argue that even though disability is socially constructed, there is an essential difference between disabled and nondisabled people associated with impairment and that people with impairments, if the oppressions were stripped away, would still have unique ways of knowing. Thomas proceeds to other arguments showing that neither binaries nor identities are fixed, that when people develop identities and identity politics and other categorical approaches, they end up excluding some 'other' and are likely to sustain some form of socially constructed oppression. Thomas values constructivism and postmodern approaches that "compel us to question and unpack taken-for-granted features of culture and discourse" (p. 117) but finds its lack of explanatory power frustrating. Thomas con-

cludes Part II by noting the usefulness of the social model in galvanizing disabled activists to take on a disabled identity in the service of political struggle and the counter narrative to the status quo medical model. Other counter narratives of race, sexuality, ethnicity, age are also useful, adding strands to and enriching the disability resistance movement.

Part III develops a theoretical approach to disability. Chapter 7 draws together "the need for a social relational model of disability, the need to theorize impairment and impairment effects and their interaction with disability, and the need to understand disability as a gendered phenomenon" (p. 123). Here Thomas thoroughly situates herself as a materialist, a perspective through which she synthesizes the premises she finds most useful in feminist analysis and Disability Studies. Quoting Marx (1972) she recalls that even though people make their own history, they do so "not under circumstances chosen by themselves but under circumstances directly encountered, given, and transmitted from the past (cited on p. 126). For example, severe segregation of people with disabilities was the product of industrialization, rendering their fate to be determined by medicine and the state; the history of the term 'disability' in Britain is bound up in production (p. 130). In addition to theorizing the social position of disabled women in relation to production and reproduction, Thomas also attends to matters of culture. In reviewing the value of the postmodern emphasis on culture creating the self, she notes that culture processes are indeed overwhelmingly privileged. In post-structuralist discourses that see the self as entirely the product of meanings, language and discourses, impaired people are not "givens" but discursively created. Rather than being caught in another sustainable dualism, Thomas argues that:

...it is quite possible simultaneously to make a conceptual distinction between impairment and disability, reconceptualize the latter as a form of social oppression, understand that bodily variations classified as impairments are materially shaped by

the interactions of social and biological factors and processes, and appreciate that impairment is a culturally constructed category which exists in particular times and places. (p. 141).

Thus Thomas transcends the typical materialist downplay of the role of cultural practices and the poststructuralist failure to acknowledge that life is a struggle for material existence for most disabled people.

The final chapter explores the divide between Disability Studies and medical sociology with the intent of encouraging dialogue between the two. Thomas asserts that there is much to learn from both, even though medical sociology uses the medical model of disability. Although medical sociologists have little or no interest in locating experience in its broader socio-structural context, they do, however, privilege social action or agency while the Disability Studies' social model of disability tends to privilege structure (p. 155). Thomas calls on Disability Studies to "overcome this dualism or at least encourage analyses that bridge agency and structure (p. 155).

Female Forms yields an excellent review of the British foundations of Disability Studies and the influences and conflicts with feminist and interpretivist analyses. Thomas has shown the basis for the next steps in Disability Studies which include transcending unsustainable dualisms, vestiges of the origins of the several factions within the field. Although there are only a few references to non-British Disability Studies scholars, those who are bridging this dualism in academe and in the streets (and attempting to do so) will find substance, validation, and potential direction in the next-generation unanswered questions from Thomas's forward thinking work.

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