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The Disability Studies Reader

Second Edition

Edited by Lennard J. Davis



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38. Fausto-Sterling, *Sexing the Body*, pp. 275–76 n. 1.
39. Fausto-Sterling, *Sexing the Body*. See also Cheryl Chase, "Affronting Reason," in Dawn Atkins (ed.), *Looking Queer: Body Image and Identity in Lesbian, Bisexual, Gay, and Transgender Communities* (New York: The Harrington Park Press, 1998); A.D. Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge, Mass.: Harvard University Press, 1998); Shelley Tremain, Review of Atkins (ed.), *Looking Queer: Body Image and Identity in Lesbian, Bisexual, Gay and Transgender Communities*, in *Disability Studies Quarterly* 18 (1998): 198–99; and Shelley Tremain, "Queering Disabled Sexuality Studies," *Journal of Sexuality and Disability* 18 (2000): 291–99.
40. Fausto-Sterling, *Sexing the Body*, pp. 147–59.
41. Butler, *Gender Trouble*, p. 143.
42. *Ibid.*, pp. 10–11.
43. See Butler, *Gender Trouble*.
44. Tom Shakespeare, "A Response to Liz Crow," *Coalition* (September 1992), p. 40; quoted in Oliver, *Understanding Disability*, p. 39.
45. The analogical arguments that disability researchers and theorists make from "sex" not only reinstitute and contribute to the naturalization and materialization of binary sex—in addition, these arguments facilitate and contribute to the naturalization and materialization of impairment. To take one example, in order to argue that degrading cultural norms and values, exclusionary discursive and social practices, and biased representations produce disability, disability theorists have come to depend upon analogical arguments that illustrate how these phenomena operate in the service of sexism (e.g., Oliver, *The Politics of Disablement*). To take another example, the analogy from sexism is used to identify inconsistencies and double standards between the treatment of sexual discrimination in public policy and law and the treatment in the same domains of disability discrimination (e.g., Anita Silvers, David Wasserman, and Mary B. Mahowald, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* [Lanham: Rowman & Littlefield, 1998]). The analogical structure of these arguments requires that one appeal to clear distinctions between males and females, and men and women, as well as assume a stable and distinct notion of impairment. In the terms of these analogical arguments, furthermore, "sex" and "impairment" are represented as separate and real entities, each with unique properties, and each of whose identity can be distinguished from that of the other. The heterosexual assumptions that condition this manner of argumentation in Disability Studies preclude consideration of the implications for work in the discipline of the questions that intersexuality raises (see Tremain, "Queering Disabled Sexuality Studies"; and Shelley Tremain, Review of Thomas, *Female Forms: Experiencing and Understanding Disability*, in *Disability & Society* 15 (2000): 825–29).
46. Cf. Paul Abberley, "The Concept of Oppression and the Development of a Social Theory of Disability," *Disability, Handicap & Society* 2 (1987): 5–19; and Carol Thomas, *Female Forms*.
47. Margrit Shildrick and Janet Price, "Breaking the Boundaries of the Broken Body," *Body & Society* 2 (1996): 93–113, p. 101.
48. *Ibid.*, p. 102.
49. *Ibid.*, pp. 101–2.
50. Foucault, "The Subject and Power"; Colin Gordon, "Governmental Rationality: An Introduction," in Graham Burchell, Colin Gordon, and Peter Miller (eds.), *The Foucault Effect: Studies in Governmentality* (Chicago: University of Chicago Press, 1991), p. 3.
51. Foucault, *The History of Sexuality*, Vol. 1, p. 93.
52. See, for example, Thomas, *Female Forms*, p. 137.
53. Michel Foucault, "Power and Sex," in *Politics, Philosophy, Culture: Interviews and Other Writings (1977–1984)*, ed. Lawrence D. Kritzman (London: Routledge, 1988), p. 84.
54. Gordon, "Governmental Rationality," p. 5.
55. Foucault, "The Birth of Biopolitics," pp. 74–77.
56. Wendy Brown, *States of Injury: Power and Freedom in Late Modernity* (Princeton: Princeton University Press, 1995), pp. 59, 65.
57. See Tremain, Review of Thomas, *Female Forms*.
58. Brown, *States of Injury*, p. 75.
59. Foucault, "The Subject and Power," p. 216.
60. Michel Foucault, "What is Enlightenment?" in *Ethics, Subjectivity and Truth*, p. 319.
61. *Ibid.*, p. 315.

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The Social Model of Disability

Tom Shakespeare

Introduction

In many countries of the world, disabled people and their allies have organised over the last three decades to challenge the historical oppression and exclusion of disabled people (Driedger, 1989; Campbell and Oliver, 1996; Charlton, 1998). Key to these struggles has been the challenge to over-medicalized and individualist accounts of disability. While the problems of disabled people have been explained historically in terms of divine punishment, karma or moral failing, and post-Enlightenment in terms of biological deficit, the disability movement has focused attention onto social oppression, cultural discourse, and environmental barriers.

The global politics of disability rights and deinstitutionalisation has launched a family of social explanations of disability. In North America, these have usually been framed using the terminology of minority groups and civil rights (Hahn, 1988). In the Nordic countries, the dominant conceptualisation has been the relational model (Gustavsson et al., 2005). In many countries, the idea of normalisation and social role valorisation has been inspirational, particularly amongst those working with people with learning difficulties (Wolfensburger, 1972). In Britain, it has been the social model of disability which has provided the structural analysis of disabled people's social exclusion (Hasler, 1993).

The social model emerged from the intellectual and political arguments of the *Union of Physically Impaired Against Segregation* (UPIAS). This network had been formed after Paul Hunt, a former resident of the Lee Court Cheshire Home, wrote to *The Guardian* newspaper in 1971, proposing the creation of a consumer group of disabled residents of institutions. In forming the organization and developing its ideology, Hunt worked closely with Vic Finkelstein, a South African psychologist, who had come to Britain in 1968 after being expelled for his anti-apartheid activities. UPIAS was a small, hardcore group of disabled people, inspired by Marxism, who rejected the liberal and reformist campaigns of more mainstream disability organisations such as the Disablement Income Group and the Disability Alliance. According to their policy statement (adopted December 1974), the aim of UPIAS was to replace segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their own lives. The policy statement defined disabled people as an oppressed group and highlighted barriers:

We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment. (UPIAS Aims paragraph 1)

Even in Britain, the social model of disability was not the only political ideology on offer to the first generation of activists (Campbell and Oliver, 1996). Other disabled-led activist groups had emerged, including the Liberation Network of People with Disabilities. Their draft Liberation Policy, published

in 1981, argued that while the basis of social divisions in society was economic, these divisions were sustained by psychological beliefs in inherent superiority or inferiority. Crucially, the Liberation Network argued that people with disabilities, unlike other groups, suffered inherent problems because of their disabilities. Their strategy for liberation included: developing connections with other disabled people and creating an inclusive disability community for mutual support; exploring social conditioning and positive self-awareness; the abolition of all segregation; seeking control over media representation; working out a just economic policy; encouraging the formation of groups of people with disabilities.

However, the organization which dominated and set the tone for the subsequent development of the British disability movement, and of disability studies in Britain, was UPIAS. Where the Liberation Network was dialogic, inclusive and feminist, UPIAS was hard-line, male-dominated, and determined. The British Council of Organisations of Disabled People, set up as a coalition of disabled-led groups in 1981, adopted the UPIAS approach to disability. Vic Finkelstein and the other BCODP delegates to the first Disabled People's International World Congress in Singapore later that year, worked hard to have their definitions of disability adopted on the global stage (Driedger, 1989). At the same time, Vic Finkelstein, John Swain and others were working with the Open University to create an academic course which would promote and develop disability politics (Finkelstein, 1998). Joining the team was Mike Oliver, who quickly adopted the structural approach to understanding disability, and was to coin the term "social model of disability" in 1983.

What Is the Social Model of disability?

While the first UPIAS Statement of Aims had talked of social problems as an added burden faced by people with impairment, the Fundamental Principles of Disability discussion document, recording their disagreements with the reformist Disability Alliance, went further:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1975)

Here and in the later development of UPIAS thinking are the key elements of the social model: the distinction between disability (social exclusion) and impairment (physical limitation) and the claim that disabled people are an oppressed group. Disability is now defined, not in functional terms, but as

the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS, 1975)

This redefinition of disability itself is what sets the British social model apart from all other socio-political approaches to disability, and what paradoxically gives the social model both its strengths and its weaknesses.

Key to social model thinking is a series of dichotomies:

1. Impairment is distinguished from disability. The former is individual and private, the latter is structural and public. While doctors and professions allied to medicine seek to remedy impairment, the real priority is to accept impairment and to remove disability. Here there is an analogy with feminism, and the distinction between biological sex (male and female) and social gender (masculine and feminine) (Oakley, 1972). Like gender, disability is a culturally and historically specific phenomenon, not a universal and unchanging essence.

2. The social model is distinguished from the medical or individual model. Whereas the former defines disability as a social creation—a relationship between people with impairment and a disabling society—the latter defines disability in terms of individual deficit. Mike Oliver writes:

Models are ways of translating ideas into practice and the idea underpinning the individual model was that of personal tragedy, while the idea underpinning the social model was that of externally imposed restriction. (Oliver, 2004, 19)

Medical model thinking is enshrined in the liberal term "people with disabilities," and in approaches that seek to count the numbers of people with impairment, or to reduce the complex problems of disabled people to issues of medical prevention, cure or rehabilitation. Social model thinking mandates barrier removal, anti-discrimination legislation, independent living and other responses to social oppression. From a disability rights perspective, social model approaches are progressive, medical model approaches are reactionary.

3. Disabled people are distinguished from non-disabled people. Disabled people are an oppressed group, and often non-disabled people and organisations—such as professionals and charities—are the causes or contributors to that oppression. Civil rights, rather than charity or pity, are the way to solve the disability problem. Organisations and services controlled and run by disabled people provide the most appropriate solutions. Research accountable to, and preferably done by, disabled people offers the best insights.

For more than ten years, a debate has raged in Britain about the value and applicability of the social model (Morris, 1991; Crow, 1992; French, 1993; Williams, 1999; Shakespeare and Watson 2002). In response to critiques, academics and activists maintain that the social model has been misunderstood, misapplied, or even wrongly viewed as a social theory. Many leading advocates of the social model approach maintain that the essential insights developed by UPIAS in the 1970s still remain accurate and valid three decades later.

Strengths of the Social Model

As demonstrated internationally, disability activism and civil rights are possible without adopting social model ideology. Yet the British social model is arguably the most powerful form which social approaches to disability have taken. The social model is simple, memorable, and effective, each of which is a key requirement of a political slogan or ideology. The benefits of the social model have been shown in three main areas.

First, the social model, called "the big idea" of the British disability movement (Hasler, 1993), has been effective *politically* in building the social movement of disabled people. It is easily explained and understood, and it generates a clear agenda for social change. The social model offers a straightforward way of distinguishing allies from enemies. At its most basic, this reduces to the terminology people use: "disabled people" signals a social model approach, whereas "people with disabilities" signals a mainstream approach.

Second, by identifying social barriers to be removed, the social model has been effective *instrumentally* in the liberation of disabled people. Michael Oliver argues that the social model is a "practical tool, not a theory, an idea or a concept" (2004, 30). The social model demonstrates that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits. This places the moral responsibility on society to remove the burdens which have been imposed, and to enable disabled people to participate. In Britain, campaigners used the social model philosophy to name the various forms of discrimination which disabled people (Barnes, 1991), and used this evidence as the argument by which to achieve the 1995 Disability Discrimination Act. In the subsequent decade, services, buildings and public transport have been required to be accessible to disabled people, and most statutory and voluntary organizations have adopted the social model approach.

Third, the social model has been effective *psychologically* in improving the self-esteem of disabled people and building a positive sense of collective identity. In traditional accounts of disability, people with impairments feel that they are at fault. Language such as "invalid" reinforce a sense of personal deficit and failure. The focus is on the individual, and on her limitations of body and brain. Lack of

self-esteem and self-confidence is a major obstacle to disabled people participating in society. The social model has the power to change the perception of disabled people. The problem of disability is relocated from the individual, to the barriers and attitudes which disable her. It is not the disabled person who is to blame, but society. She does not have to change, society does. Rather than feeling self-pity, she can feel anger and pride.

Weaknesses of the Social Model

The simplicity which is the hallmark of the social model is also its fatal flaw. The social model's benefits as a slogan and political ideology are its drawbacks as an academic account of disability. Another problem is its authorship by a small group of activists, the majority of whom had spinal injury or other physical impairments and were white heterosexual men. Arguably, had UPIAS included people with learning difficulties, mental health problems, or with more complex physical impairments, or more representative of different experiences, it could not have produced such a narrow understanding of disability.

Among the weaknesses of the social model are:

1. The neglect of impairment as an important aspect of many disabled people's lives. Feminists Jenny Morris (1991), Sally French (1993), and Liz Crow (1992) were pioneers in this criticism of the social model neglect of individual experience of impairment:

As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability. [Crow, 1992, 7]

The social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem. Whereas other socio-political accounts of disability have developed the important insight that people with impaired are disabled by society as well as by their bodies, the social model suggests that people are disabled by society not by their bodies. Rather than simply opposing medicalization, it can be interpreted as rejecting medical prevention, rehabilitation or cure of impairment, even if this is not what either UPIAS, Finkelstein, Oliver, or Barnes intended. For individuals with static impairments, which do not degenerate or cause medical complications, it may be possible to regard disability as entirely socially created. For those who have degenerative conditions which may cause premature death, or which any condition which involves pain and discomfort, it is harder to ignore the negative aspects of impairment. As Simon Williams has argued,

... endorsement of disability solely as social oppression is really only an option, and an erroneous one at that, for those spared the ravages of chronic illness. (Williams, 1999, 812)

Carol Thomas (1999) has tried to develop the social model to include what she calls "impairment effects," in order to account for the limitations and difficulties of medical conditions. Subsequently, she subsequently suggested that a relational interpretation of the social model enables disabling aspects to be attributed to impairment, as well as social oppression:

once the term "disability" is ring-fenced to mean forms of oppressive social reactions visited upon people with impairments, there is no need to deny that impairment and illness cause some restrictions of activity, or that in many situations both disability and impairment effects interact to place limits on activity. (2004, 29)

One curious consequence of the ingenious reformulation is that only people with impairment who face oppression can be called disabled people. This relates to another problem:

2. The social model assumes what it needs to prove: that disabled people are oppressed. The sex/gender distinction defines gender as a social dimension, not as oppression. Feminists claimed that gender relations *involved* oppression, but did not define gender relations *as* oppression. However, the social model defines disability as oppression. In other words, the question is not whether disabled people are oppressed in a particular situation, but only the extent to which they are oppressed. A circularity enters into disability research: it is logically impossible for a qualitative researcher to find disabled people who are not oppressed.

3. The analogy with feminist debates about sex and gender highlights another problem: the crude distinction between impairment (medical) and disability (social). Any researcher who does qualitative research with disabled people immediately discovers that in everyday life it is very hard to distinguish clearly between the impact of impairment, and the impact of social barriers (see Watson, 2002; Sherry, 2002). In practice, it is the interaction of individual bodies and social environments which produces disability. For example, steps only become an obstacle if someone has a mobility impairment: each element is necessary but not sufficient for the individual to be disabled. If a person with multiple sclerosis is depressed, how easy is it to make a causal separation between the effect of the impairment itself; her reaction to having an impairment; her reaction to being oppressed and excluded on the basis of having an impairment; other, unrelated reasons for her to be depressed? In practice, social and individual aspects are almost inextricable in the complexity of the lived experience of disability.

Moreover, feminists have now abandoned the sex/gender distinction, because it implies that sex is not a social concept. Judith Butler (1990) and others show that what we think of as sexual difference is always viewed through the lens of gender. Shelley Tremain (2002) has claimed similarly that the social model treats impairment as an unsocialized and universal concept, whereas, like sex, impairment is always already social.

4. The concept of the barrier-free utopia. The idea of the enabling environment, in which all socially imposed barriers are removed, is usually implicit rather than explicit in social model thinking, although it does form the title of a major academic collection (Swain et al., 1993). Vic Finkelstein (1981) also wrote a simple parable of a village designed for wheelchair users to illustrate the way that social model thinking turned the problem of disability on its head. Yet despite the value of approaches such as Universal Design, the concept of a world in which people with impairments were free of environmental barriers is hard to operationalize.

For example, numerous parts of the natural world will remain inaccessible to many disabled people: mountains, bogs, beaches are almost impossible for wheelchair users to traverse, while sunsets, bird-song, and other aspects of nature are difficult for those lacking sight or hearing to experience. In urban settings, many barriers can be mitigated, although historic buildings often cannot easily be adapted. However, accommodations are sometimes incompatible because people with different impairments may require different solutions: blind people prefer steps and defined curbs and indented paving, while wheelchair users need ramps, dropped curbs, and smooth surfaces. Sometimes, people with the same impairment require different solutions: some visually impaired people access text in Braille, others in large print, audio tape or electronic files. Practicality and resource constraints make it unfeasible to overcome every barrier: for example, the New York subway and London Underground systems would require huge investments to make every line and station accessible to wheelchair users. A copyright library of five million books could never afford to provide all these texts in all the different formats that visually impaired users might potentially require. In these situations, it seems more practical to make other arrangements to overcome the problems: for example, Transport for London have an almost totally accessible fleet of buses, to compensate those who cannot use the tube, while libraries increasingly have arrangements to make particular books accessible on demand, given notice.

Moreover, physical and sensory impairments are in many senses the easiest to accommodate. What would it mean to create a barrier free utopia for people with learning difficulties? Reading and writing and other cognitive abilities are required for full participation in many areas of contemporary life in developed nations. What about people on the autistic spectrum, who may find social contact difficult

to cope with: a barrier free utopia might be a place where they did not have to meet, communicate with, or have to interpret other people. With many solutions to the disability problem, the concept of addressing special needs seems more coherent than the concept of the barrier free utopia. Barrier free enclaves are possible, but not a barrier free world.

While environments and services can and should be adapted wherever possible, there remains disadvantage associated with having many impairments which no amount of environmental change could entirely eliminate. People who rely on wheelchairs, or personal assistance, or other provision are more vulnerable and have fewer choices than the majority of able-bodied people. When Michael Oliver claims that

An aeroplane is a mobility aid for non-flyers in exactly the same way as a wheelchair is a mobility aid for non-walkers. (Oliver, 1996, 108)

his suggestion is amusing and thought provoking, but cannot be taken seriously. As Michael Bury has argued,

It is difficult to imagine any modern industrial society (however organised) in which, for example, a severe loss of mobility or dexterity, or sensory impairments, would not be 'disabling' in the sense of restricting activity to some degree. The reduction of barriers to participation does not amount to abolishing disability as a whole. (Bury, 1997, 137)

Drawing together these weaknesses, a final and important distinction needs to be made. The disability movement has often drawn analogies with other forms of identity politics, as I have done in this chapter. The disability rights struggle has even been called the "Last Liberation Movement" (Driedger, 1989). Yet while disabled people do face discrimination and prejudice, like women, gay and lesbian people, and minority ethnic communities, and while the disability rights movement does resemble in its forms and activities many of these other movements, there is a central and important difference. There is nothing intrinsically problematic about being female or having a different sexual orientation, or a different skin pigmentation or body shape. These other experiences are about wrongful limitation of negative freedom. Remove the social discrimination, and women and people of color and gay and lesbian people will be able to flourish and participate. But disabled people face both discrimination and intrinsic limitations. This claim has three implications. First, even if social barriers are removed as far as practically possible, it will remain disadvantageous to have many forms of impairment. Second, it is harder to celebrate disability than it is to celebrate Blackness, or Gay Pride, or being a woman. "Disability pride" is problematic, because disability is difficult to recuperate as a concept, as it refers either to limitation and incapacity, or else to oppression and exclusion, or else to both dimensions. Third, if disabled people are to be emancipated, then society will have to provide extra resources to meet the needs and overcome the disadvantage which arises from impairment, not just work to minimize discrimination (Bickenbach et al., 1999).

Beyond the Social Model?

In this chapter, I have tried to offer a balanced assessment of the strengths and weaknesses of the British social model of disability. While acknowledging the benefits of the social model in launching the disability movement, promoting a positive disability identity, and mandating civil rights legislation and barrier removal, it is my belief that the social model has now become a barrier to further progress.

As a researcher, I find the social model unhelpful in understanding the complex interplay of individual and environmental factors in the lives of disabled people. In policy terms, it seems to me that the social model is a blunt instrument for explaining and combating the social exclusion that disabled

people face, and the complexity of our needs. Politically, the social model has generated a form of identity politics which has become inward looking and separatist.

A social approach to disability is indispensable. The medicalization of disability is inappropriate and an obstacle to effective analysis and policy. But the social model is only one of the available options for theorizing disability. More sophisticated and complex approaches are needed, perhaps building on the WHO initiative to create the International Classification of Functioning, Disability and Health. One strength of this approach is the recognition that disability is a complex phenomenon, requiring different levels of analysis and intervention, ranging from the medical to the socio-political. Another is the insight that disability is not a minority issue, affecting only those people defined as disabled people. As Irving Zola (1989) maintained, disability is a universal experience of humanity.

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17

Narrative Prosthesis and the Materiality of Metaphor

David Mitchell and Sharon Snyder

Literature and the Undisciplined Body of Disability

This chapter prefaces the close readings to come by deepening our theory of narrative prosthesis as shared characteristics in the literary representation of disability. We demonstrate one of a variety of approaches in disability studies to the "problem" that disability and disabled populations pose to all cultures. Nearly every culture views disability as a problem in need of a solution, and this belief establishes one of the major modes of historical address directed toward people with disabilities. The necessity for developing various kinds of cultural accommodations to handle the "problem" of corporeal difference (through charitable organizations, modifications of physical architecture, welfare doles, quarantine, genocide, euthanasia programs, etc.) situates people with disabilities in a profoundly ambivalent relationship to the cultures and stories they inhabit. The perception of a "crisis" or a "special situation" has made disabled people the subject of not only governmental policies and social programs but also a primary object of literary representation.

Our thesis centers not simply upon the fact that people with disabilities have been the object of representational treatments, but rather that their function in literary discourse is primarily twofold: disability pervades literary narrative, first, as a stock feature of characterization and, second, as an opportunistic metaphorical device. We term this perpetual discursive dependency upon disability *narrative prosthesis*. Disability lends a distinctive idiosyncrasy to any character that differentiates the character from the anonymous background of the "norm." To exemplify this phenomenon, the opening half of this chapter analyzes the Victorian children's story *The Steadfast Tin Soldier* in order to demonstrate that disability serves as a primary impetus of the storyteller's efforts. In the second instance, disability also serves as a metaphorical signifier of social and individual collapse. Physical and cognitive anomalies promise to lend a "tangible" body to textual abstractions; we term this metaphorical use of disability the *materiality of metaphor* and analyze its workings as narrative prosthesis in our concluding discussion of Sophocles' drama *Oedipus the King*. We contend that disability's centrality to these two principle representational strategies establishes a conundrum: while stories rely upon the potency of disability as a symbolic figure, they rarely take up disability as an experience of social or political dimensions.

While each of the chapters that follow set out some of the key cultural components and specific historical contexts that inform this history of disabled representations, our main objective addresses the development of a representational or "literary" history. By "literary" we mean to suggest a form of writing that explicitly values the production of what narrative theorists such as Barthes, Blanchot, and Chambers have referred to as "open-ended" narrative.¹ The identification of the open-ended narrative differentiates a distinctively "literary" component of particular kinds of storytelling: those texts that not only deploy but explicitly foreground the "play" of multiple meanings as a facet of their discursive production. While this definition does not overlook the fact that all texts are inherently