

A Disability Lens on Sociolegal Research: Reading *Rights of Inclusion* from a Disability Studies Perspective

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DAVID M. ENGEL AND FRANK W. MUNGER. *Rights of Inclusion: Law and Identity in the Life Story of Americans with Disabilities*. Chicago: University of Chicago Press, 2003. Pp. xii + 274. Cloth \$56.00; paper \$19.00.

We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on breathing tubes, following our guide dogs, puffing and sipping on the mouth sticks that propel our motorized chairs. We may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system. We are bound together, not by this list of our collective symptoms but by the social and political circumstances that have forged us as a group. (Linton 1998, 4)

WE ARE EVERYWHERE

Simi Linton's eloquent introduction to her book *Claiming Disability* evokes the central premise—as well as the central problem—of the majority of contemporary disability research. The recognition and reminder that “we are everywhere these days” is directed not only at a reluctant public sphere, slow to provide the disability rights and accessibility proscribed for by law, it is also directed at the academy, equally slow to see disability as an important new site for analysis. Thinking about disability has traditionally been relegated to the applied fields—rehabilitation, special education, counseling, and social

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work—where disability is seen as something to be fixed or mitigated, rather than, as Linton would suggest, a social and political category that powerfully shapes identity. People with disabilities, she contends, are taking back the public sphere and are claiming a space that has long been denied to them. Most importantly, however, they are forging into the world with a sense of collective consciousness, a sense of togetherness that is not generated by what “ails” them but by the way society responds to their disabilities.

The claim that disability is a social construction and not the inevitable result of personal injury or illness has revolutionized the ways that disability is being talked about in the academy and in politics. In the United States, the 1990 Americans with Disabilities Act (ADA), as well as Section 504 of the 1973 Rehabilitation Act, have long been considered the inaugural document for this new paradigm of disability. The ADA defines disability discrimination as a civil rights issue and identifies people with disabilities as a protected minority. It explains the exclusion of people with disabilities from the public sphere not as a result of personal shortcomings or defects but as a direct result of inaccessible social environments. Seeing the world in this way requires a radical shift in perspective. It forces us to question social arrangements that were previously seen as natural and inevitable for not fully responding to the diversity of needs represented it. The true cause of a disability, according to this social model of disability, is not a person’s physical or mental impairment but rather the disabling environments and social structures surrounding that person. Accordingly, it has empowered people to make claims such as, “I am not disabled by the fact that I can’t walk, but by the fact that your building is not wheelchair accessible,” or, “I do not feel disabled being Deaf, but the lack of sign language interpreters is limiting my ability to communicate with those who hear.”

The ADA and the new paradigm of disability that it embodies have issued a profound challenge to American disability law and policy. How to create a society that is truly inclusive? How to provide people with disabilities with the same opportunities in employment, education, housing, health care, and public transportation provided for the nondisabled? How to talk about equal rights and special needs when it comes to providing equal access? The implications of the ADA mandate for disability law and policy have been widely debated in the legal literature (Berg 1999; Burgdorf 1997; Colker 1999, 2005; Francis 2000; Locke 1997). With the publication of *Rights of Inclusion*, we now also have a springboard from which to launch sophisticated discussions of what the ADA has meant for the lives of people with disabilities. How, for example, has an awareness of the ADA’s equal employment mandate shaped the career trajectories of workers with disabilities? How does the timing of the onset or diagnosis of a disability shape a person’s identity as a capable student or worker with a disability? What can we learn from life story narratives about the ways that disability rights become active or remain inactive? These and other issues form a thought-provoking and immensely readable account of the state of disability rights in the United States today.

Rights of Inclusion is an important new discussion of disability rights consciousness in the best tradition of law and society scholarship, where, by the time of this publication, it will undoubtedly have found a large readership already. Limiting its impact to law and society scholarship is doing it a disservice, however. Engel and Munger's new book is equally important for another growing academic community—that of disability studies.

This essay will read *Rights of Inclusion* from a disability studies perspective and ponder the ways it can contribute to a more multifaceted and nuanced understanding of disability rights and identity. It will take the book's central premise—the recursive relationship between rights and identity—and outline its implications for disability studies. More broadly, it seeks to build a bridge between two modes of inquiry—law and society research and disability studies—and shows how the book pushes these boundaries and allows us to ask more sophisticated questions about disability rights consciousness. It is to be a conversation between sociolegal and disability studies, asking what can emerge when two modes of inquiry speak to each other. *Rights of Inclusion* is the first book-length treatment of disability consciousness from a sociolegal perspective. In that sense it embodies all the promises and challenges of interdisciplinary research: What happens when sociolegal inquiry ventures into the field of disability studies? How will the two engage each other? What do they need to learn from each other?

I begin with an overview of disability studies as an academic discipline and the theoretical models it grapples with. Next, to highlight the contribution *Rights of Inclusion* makes to disability studies, I will explore ways disability rights and the ADA have been addressed in the existing disability studies literature. What is the role of the ADA in the disability rights community, and how can the book point to new ways of thinking about rights and identity? After this background I will focus on the recursive relationship between rights and identity and place it in conversation with disability theory. Three arguments emerge: a question of the separation of self from disability, a dilemma of disability regarding invisible disabilities, and a question of language and labels. Finally, the essay will discuss some of the methodological issues raised by the book, which have been widely discussed in the disability research community and which should raise larger questions for law and society scholarship. By complicating the significance of the disability label, *Rights of Inclusion* provokes and invokes the best of disability scholarship, opening the doors to dialogue and connections across disciplines.

WHAT IS DISABILITY STUDIES?

Disability studies is an interdisciplinary field developed in the mid-1980s that invites scholars to think about disability not as a question of medical cures or rehabilitation but as a social category on par with race, gender, class,

and sexual orientation. According to Simi Linton (1998, 2), disability studies “takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing, but, more crucially, the meaning we make of those variations.” Taking such an approach opens disability as an exciting and useful new site of analysis for the social sciences and humanities, liberating it from its traditional application in the applied fields. Again, Linton explains the origin of disability studies as “as a counterpoint to the medicalized perspectives on disability emanating from the applied fields, and in response to the marginalization and distortions apparent across the curriculum” (1998, 2).

Disability studies has its own academic organization, the Society for Disability Studies (SDS), which publishes a journal and holds an annual conference that attracts scholars from a growing number of disciplines. The society’s initials, SDS, were chosen deliberately to imitate 1960s-era student activism by the Students for a Democratic Society and thus to remind members to work for social change. Disability studies evolved along with disability activism, and its founders envisioned it as a site that would foster strong connections between research and advocacy.¹ Disability is to be seen as a social construct, rather than an individual deficit and people with disabilities as a minority group, similar to other minority groups based on race and ethnicity. The suggestion here is that disability research is inherently political: it is to be guided by a commitment to recognizing and ending the political and social marginalization of people with disabilities. To that end, research in disability studies should use the perspective and experiences of people with disabilities in all stages of research production and actively encourage the participation of stakeholders in the research process.

I will address the implications of this political (as well as methodological) mandate later in this essay. What is important to mention at this point are some of the conceptual and political differences in the ways disability studies is viewed in its two principal homes: the United States and Great Britain. Great Britain is commonly considered the academic home of the social model of disability, which was initiated by the Union of the Physically Impaired against Segregation (UPIAS) during the 1970s, and first theorized in the writings of Paul Abberly, Colin Barnes, Michael Oliver, and others. In the United States, disability studies became more prominent after the passage of the Americans with Disabilities Act, the first comprehensive antidiscrimination law for people with disabilities in the world. In contrast to the emphasis on liberal legalism in American disability theory and activism, the social model

1. The SDS website <http://www.uic.edu/orgs/sds> (accessed October 20, 2006) gives a history of the development of disability studies, as well as guidelines for universities who want to establish disability studies programs. The National Institute on Disability and Rehabilitation Research (NIDRR) within the Department of Education, has been sponsoring research and promoting the establishment of disability studies programs.

in Great Britain remains firmly embedded in a radical critique of capitalism. The difference between the British and U.S. theorizing of the social model is also reflected in the ways disability studies has set foot in the academy: in Great Britain, it is part of social science departments, whereas, in the United States, disability studies is most prominently represented in the humanities.

Models of Disability

Just as its big sister, women's studies, emerged with feminist activism, disability studies evolved along with the disability rights movement. In an international conference to promote disability studies as a distinctive academic discipline, the late David Pfeiffer, one of the founding scholars in disability studies in the United States, affirmed this connection: "Viewing the disability experience as one of discrimination is the most fruitful for both research and advocacy, 'he said.' It unifies both the disability movement and disability studies" (NIDRR 2000).

Disability studies scholarship centers most of its theorizing, analysis, and criticism on what is commonly known as social model of disability. In contrast to the traditional medical model of disability, the social model seeks to take the focus away from the disabled individual—to be fixed, cured, or rehabilitated—and focus instead on the ways that the experience of disability is a product of disabling environments, social structures, and stereotypes (Morris 1991; Oliver 1990). Generally speaking, the medical model holds a person's physical or mental impairments responsible for disadvantages associated with disabilities, whereas the social model explains these disadvantages as a product of negative attitudes and systemic discrimination that result in system-wide barriers to information, communication, and the physical environment.

When translated into policy, the medical model relies on rehabilitation and welfare facilities to mediate or accommodate the effects of disabilities. Typically, this occurs by establishing separate facilities, such as nursing homes, sheltered workshops, and special education schools, separate from the facilities that serve the nondisabled. The assumption here is that rather than making mainstream institutions accessible, the needs for people with disabilities are better served in separate facilities that can be constructed to meet very specialized needs (Waddington 1994). This exclusion is not seen as discriminatory, as the social model would suggest, but as a natural outcome of a person's physical or mental deviation from the nondisabled norm.

The social model, in contrast, would do away with the parallel track and focus on ways to make social environments accessible and reform social institutions to include people with disabilities. The assumption is that once the nondisabled majority gains increasing contact with their disabled peers, discriminatory attitudes and fears of the unknown "other" will disappear.

Remedying the effects of a discriminatory society is a form of civil rights enforcement similar to that of other minority groups. Following the civil rights model, then, legal rights and remedies become central players in this new understanding of what it means to live with a disability.

In the United States, which became an internationally acknowledged leader in rights-based activism during the struggle for Section 504 and then especially after the passage of the ADA (Heyer 2002), the social model is conceptualized as a “minority rights model” to mark disability as a second-generation social movement that follows a legal trajectory marked by the civil rights and women’s movements (Scotch 2001). The civil rights approach is enshrined in the Americans with Disabilities Act, which outlaws discrimination on the basis of disability in employment, public access, and public services. The ADA expands on the classic nondiscrimination principle with its mandate to provide “reasonable accommodations” to “otherwise qualified” individuals who, in the case of employment, would not be able to perform the “essential functions” of a job without these accommodations. This is a step toward more affirmative equality guarantees that have been widely contested in the courts and, at the same time and perhaps ironically, cemented support for the promises of liberal legalism. The central focus of much of disability rights activism and disability studies theorizing has been on expanding existing civil rights guarantees to include the needs of people with disabilities and expanding public awareness and acceptance for this extension.

This is a very broad overview of the context against which readers from the disability studies community will approach the life stories documented in *Rights of Inclusion*. Engel and Munger’s careful examination of the multiple ways that their subjects both embrace and reject disability rights consciousness adds a rich tapestry of stories to both illustrate and challenge some of the central premises of the social model.

Disability Rights and Identities

Engel and Munger’s discussion of the recursive relationship between rights and identity has powerful implications for some of the central themes emerging from the social model and disability studies that I will outline below. The central argument of the recursive relationship between rights and identity is based on the idea that identity determines how and when rights become active and yet that the recognition of rights can also shape one’s identity. “Rights shape identities in a variety of ways throughout the life cycle, and the identities thus constituted determine how and when the rights holder turns to rights as a framework for interpreting perceived experiences of unfairness” (Engel and Munger 2003, 80).

This recognition lies at the core of disability studies. Disability scholarship has produced rich tapestries of studies showing how rights—or, rather, the

absence of rights—have profoundly impacted the formation of disability identities (Davis 1997; Fries 1997; Keith 1994). Documenting the history of disability in the United States has meant documenting the ways that disability law and policy has, in the not too distant past, treated people with disabilities as helpless, unwanted, stigmatized, and ultimately right-less individuals that could not be expected to participate in some of the most basic activities of social and political citizenship: learning, working, and parenting. The disability studies project thus has focused on producing life stories documenting the effect of life in nursing homes, dealing with the rehabilitation system, with inaccessible classrooms, low expectations from teachers and peers, of endless waiting for housing, for a job, for the wheelchair to be fixed, for the sign language interpreter to arrive, for city hall to install a ramp. The focus of much of the disability studies literature, especially the early writings, was on documenting the complex and interrelated relationship between disability and identity, much of which centers on the daily inequalities by a society not fully embracing the great diversity of its citizens.

The law remains a relatively unexamined force in these accounts. While there is a growing body of legal scholarship on disability rights litigated in the courts, there is little attention to rights that have been forgone, or to the impact of disability rights in the identity of “ordinary” people with disabilities. I emphasize “ordinary” because some exceptions to this claim are worth mentioning here. Two recent collections of narratives, interviews, and short stories ask directly about the impact of disability rights in their subjects’ lives and self-understanding. Ruth O’Brien’s *Voices from the Edge* (2004) features fictional and real narratives by people with disabilities to illustrate different areas of everyday life in which they experience discrimination. O’Brien then illustrates these with background on the political and legal response to this discrimination. Andrew Potok’s *A Matter of Dignity: Changing the World of the Disabled* (2002) consists of interviews with activists, lawyers, teachers, and small business owners in the disability and rehabilitation fields. Both of these books begin with the premise that the ADA is a powerful force in the lives of people with disabilities that must be documented. Their approach is the direct opposite to Engel and Munger’s, who wish to understand the ADA effect by not asking about the law directly but rather by looking at where, when, and how it emerges in their subjects’ narratives without prompting. This is an important difference in approach to understanding the impact of the law. The other important difference is Engel and Munger’s insistence on interviewing what we would consider ordinary people with disabilities, whereas O’Brien and Potok focus on people deeply imbedded in the disability rights movement or other communities that helped them challenge traditional assumptions about disability. The presence of a community with shared experiences will have a profound impact on a person’s sense of self. None of the subjects interviewed in *Rights of Inclusion* were involved in social or political associations regarding their disability, which

will make readers wonder how their experiences would have been different had they been grounded in connection with others.²

Another important addition to these studies is a 1995 report by the National Council on Disability, a government agency charged with reviewing federal disability policy. The Council conducted town meetings in all fifty states and collected statements demonstrating the impact of the ADA on the life experiences of disabled Americans (NCD 1995). Not surprisingly, all of these narratives offer enthusiastic support of the ADA's liberating potential—the ways that it has created accessible environments, raised public awareness about disability issues, and strengthened the roles and self-image of people with disabilities.³ Comments, such as the ones below, speak to the ways that the mere presence of the ADA has sent important signals to the disability community.

Because of the ADA, I have more of the opportunities that other people have. Now I feel like a participant in life, not a spectator. (Brenda Henry, Kansas)

A successful person with a disability was once thought of as unusual. Now successful people with disabilities are the rule. It's the ADA that has opened the door. (Donna Smith-Whitty, Mississippi)

In another important difference to Engel and Munger's study, these narratives are one-time comments offering general support for the basic equality premise of the ADA—something that we would expect few people in the disability community to reject. Engel and Munger's life narratives paint a more complex and ultimately richer and more rewarding picture of the role of disability rights in peoples' lives. But the difference is important in that it shows how, on the face of it, the ADA is rightly seen as an important political and moral victory for people with disabilities. Support for the law is not necessarily coupled with the expectation of lodging formal grievances in protest of discriminatory behavior. Rather, the ADA represents a long overdue recognition that social discrimination is pervasive and that eradicating it is now a matter of federal policy. Despite this firm support for the ADA, there is little to no engagement with the ways this formal liberation impacts everyday life experiences. *Rights of Inclusion* provides this missing link and rightly reminds disability studies scholarship that it is time to pay attention to both the effect of rights and the effect of their absence.

2. It also raises the question of the impact of social movements in generating identities. The interviews in *Rights of Inclusion* points to the need for a comprehensive study of how activism in disability-related groups shapes disability identity and a sense of disability rights consciousness. (I am grateful to Anna Maria Marshall for pointing this out to me.)

3. See also the Department of Justice's status report on the tenth anniversary of the ADA, "Enforcing the ADA: Looking Back on a Decade of Progress," <http://www.usdoj.gov/crt/ada/pubs/10thrt.htm> (accessed October 20, 2006).

The Role of the ADA in the Disability Community

Disability organizations have been eager to show broad support for the ADA both within the disabled and nondisabled populations. A 1999 survey of public support conducted by the National Organization on Disability (NOD) showed that two-thirds of respondents had heard of the ADA, and that among these, nearly nine out of ten (87 percent) supported and approved of the law (NOD 1999). Perhaps most significantly, 75 percent of those familiar with the ADA believed its benefits to people with disabilities outweighed potential costs to businesses. Only 17 percent thought that the law was too expensive. Additionally, a large majority (between 85 and 95 percent) supported the main premises of the ADA's employment nondiscrimination mandate, the provisions for reasonable accommodations, and accessible transportation and public places.

A 2000 NOD/Harris survey of Americans with disabilities showed similar support, although not as enthusiastic as in the nondisabled population. Sixty-three percent of people with disabilities said that life had improved, and 28 percent attributed this improvement to the ADA. In comparison, 84 percent of the nondisabled population in the 1999 survey felt that the ADA improved the quality of life for people with disabilities. In another important difference, people with severe disabilities were less likely to say that things had improved since the passage of the ADA than people with slight disabilities (55 percent versus 74 percent, respectively).

Other empirical accounts have analyzed the perceptions of people with disabilities as to the ADA's accessibility mandates (ADA Titles II, III, and IV), rather than the more contentious and heavily litigated employment provisions (Hinton 2003). I include these statistics not to challenge or complete Engel and Munger's account of the ADA's role in the lives of people with disabilities. Rather, they serve as important reminders of the importance of the faith in the law as a tool to recognize and remedy discrimination. Disability scholarship and activism is deeply invested in the future of the ADA and its continued public support. It is against this backdrop that *Rights of Inclusion* lays out its trump card: if ADA rights hold such an important place in the disability imagination, then why aren't they invoked more frequently? Disability scholars will be surprised at a central—but unsurprising to law and society scholars—finding in the book: none of their sixty interview subjects had filed an ADA lawsuit or even consulted a lawyer when they experienced disability-related discrimination (Engel and Munger 2003, 91). The reluctance to mobilize civil rights legislation despite the general support for such laws in the communities intended to benefit from them has been widely explored by sociolegal scholarship. A conversation between the two disciplines should help disability scholars understand what *Rights of Inclusion* documents so beautifully—the great ambivalence people with disabilities have toward their rights as “disabled” and toward mobilizing the ADA to address the

discrimination they face. The life stories in Engel and Munger's book should provoke the kind of critical engagement with legal liberalism in the disability community that sociolegal scholars have come to expect from their discipline.

Discursive Frameworks: Racial Justice, Market Privilege, and Religion

It is in this context—the question of what prevents disability rights from becoming active—that Engel and Munger's chapter on discursive frameworks becomes particularly meaningful for disability scholarship. The chapter discusses three types of discourse—the discourse of racial justice, of the market, and of faith, which can either enable people with disabilities to interpret their experiences as discriminatory and therefore as ADA violations or, in contrast, compel them to view their experiences as a natural and appropriate, as something that just cannot be helped. The discourse on racial justice is perhaps the most powerful of these. Both disability law and activism constructs disability rights as a natural extension of race-based civil rights doctrine, constructing the analogy between discrimination on the basis of disability and that on the basis of race (Jonathan Young 1997). The power of the civil rights analogy has provided a well-paved terrain for disability advocates and provided considerable legitimacy, as well as a familiar vocabulary, to their cause (Diller 2003; Schriener and Scotch 2003). At the same time, however, many of Engel and Munger's interviewees, most of whom are white, feel reluctant to embrace disability rights because of what they perceive as the racial connotation of rights discourse. Following common assumptions, they conflate civil rights with special privileges, hiring quotas, and assume (mistakenly) that the ADA is an affirmative action statute, requiring employers (again, mistakenly) to hire unqualified disabled workers over their qualified nondisabled peers. This explains why “white interviewees, in particular, feel precluded from invoking civil rights because they see their own identities as fundamentally different from those of African Americans and their experience of disability as unique. In a sense, they view the category of rights as already filled by a social group to which they do not belong” (Engel and Munger 2003, 145). Moreover, they avoid rights discourse to explain the discriminatory experiences they face because, “to do so would equate them with a group they are unwilling to embrace as allies, a group toward which they themselves may even feel racial animosity” (147).

This line of thinking is closely echoed by the discourse of the market that shapes the ways that people with disabilities understand their employment experiences. This discourse uses economic arguments and cost-benefit analyses to debate the reasonableness of accommodating a worker with a disability and, as such, focuses on the employer's bottom line rather than on employee rights. As employees, individuals with disabilities “believe that the burden is on them to meet the employer's expectations rather than demand that

the employer incur additional costs for their benefit” (155). This tendency to privilege employer needs over individual rights explains the reluctance to ask for accommodations, which still carry the stigma of special—and thus undeserving and unfair—rights. Disability employment litigation confirms this trend to privilege the cost-benefit analysis (expressly forbidden in the EEOC’s Guidance for ADA interpretation) in determining what makes an accommodation reasonable⁴ and, by extension, privileges employer autonomy over employee rights.⁵ Reading the ways that Engel and Munger’s interviewees grapple with the power of the market discourse—how can I ask for reasonable accommodations and still consider myself a qualified employee and an asset to my company—reflects a larger dilemma inherent in the ADA’s employment provisions. The statute’s emphasis on reasonable accommodations as a central piece in the promise of equal opportunities challenges deeply embedded assumptions about market neutrality, meritocracy, and equal treatment. The extent to which we are comfortable asking for reasonable accommodations, not as a form of affirmative action or special rights, but as a form of equal opportunities, reflects the degree to which we can acknowledge that business practices are not neutral and that the identity of a worker still privileges a nondisabled norm.

The tendency to accept the status quo as inevitable is also reflected in the discursive framework of faith. This discourse emphasizes forgiveness and generosity, making it difficult to address discriminatory treatment and invoke disability rights in an adversarial fashion that might violate religious doctrine. One of Engel and Munger’s interview subjects is a born-again Baptist, who feels this dilemma keenly: “the more she adheres to her Christian beliefs, the more she thinks that she should forgive those who treat her unfairly. Yet her knowledge of disability law makes her keenly aware of treatment that could be considered a violation of her rights” (166). Religious discourse, along with that of the market and or racial justice, is familiar discourse in everyday life that powerfully shapes individuals’ sense of justice and unfairness. The interplay of disability rights with these discourses, as Engel and Munger argue, becomes part of a broader process through which people with disabilities consider the resources available to them and construct their understandings of self and work (167). The view of disability rights in relation to these discourses can provide a context for other types of disability scholarship, especially that in the applied fields. Disability scholars, looking to improve access to employment, education, or health care or to enhance advocacy or

4. See, for example, *Borkowski v. Valley Central School District*, 63 F.3d 131 (2nd Cir. 1995) and *Vande Zande v. State of Wisconsin Department of Administration* 44 F.3d 538 (7th Cir. 1995). Both the conservative Seventh Circuit and the liberal-leaning Second Circuit ruled that the cost-benefit analysis is appropriate for the inquiry into reasonableness of accommodations and for the undue hardship defense for employers.

5. See Ruth Colker’s (1999) well-cited argument that over 90 percent of ADA employment cases are ruled in favor of the defendant.

independent living skills, must consider the complexity in which these kinds of programs, all emphasizing disability rights, interplay with the larger discourses described in this chapter. Disability scholars might focus on the book's arguments on the significance of the disability label, something that is well theorized in the disability literature and thus presents familiar territory, but they would be remiss to ignore the important discussions on discursive frameworks.

Separating Self from Disability

A principal finding that should be of tremendous interest to disability scholars is the central argument surrounding the significance of the disability label. Engel and Munger argue that, "those who tend to draw clear distinctions between their disabilities and their selves, hold equally clear conceptions of their entitlement to participate in mainstream social settings. Because their disabilities do not dominate their understandings of who they are, they see themselves as essentially similar to others who attend school and pursue employment" (68). In other words, those able to establish clear boundaries between their disability and their sense of self are more likely to invoke rights than those for whom the lines are blurred. Those without such clear boundaries are more likely to question perhaps not their right to participate fully in mainstream activities but rather wonder whether they should invoke rights to receive the accommodations to make this possible. There is no space in their lives in which rights could become active.

The life stories told in *Rights of Inclusion* demonstrate the effect of this separation powerfully. Of course, race, class, and gender will contribute to how a disability is experienced, and the authors dedicate an entire chapter to an exploration of the ways that disability is gendered. While this is an important recognition that has been widely theorized by disability scholarship (Fine and Ash 1988; Hans and Patri 2003; Hillyer 1993), the book is much more successful in complicating notions of disability identity regarding the question of how, when, and by whom the disability was defined. Timing is especially important here—an early onset or diagnosis of a disability will often familiarize potential rights holders and family members with the benefits of accommodations, especially when they occur in educational settings. For example, the diagnosis of a learning disability is often experienced as a turning point in a student's recognition that academic difficulties are not necessarily caused by a lack of intelligence. As Engel and Munger argue, a diagnosis will profoundly impact the "narrative of self" (45–46) that one continuously composes and revises and that determines the relationship between the self and the disability. As an example of this process, consider Jill Golding, a woman diagnosed with learning disabilities in her twenties, as she reinterprets the story of her childhood shortcomings with her later awareness of rights.

Jill now tells her life story in terms of the denial of her legal right to educational accommodations. Armed with a new perception of her past and her current rights and capabilities, Jill plans a career in nursing that would have been impossible in the absence of rights. The obstacles that she faces—like those she faced during childhood—are now identified as the product of discrimination or illegality rather than personal shortcomings (95).

Rights have made a tremendous difference to Jill's identity and the way she talks about her past and future life with a disability. This new narrative is based on her ability to view her disability as something separate from her self and thus not a determinant of her future opportunities. The idea of separating self from disability represents a powerful challenge to mainstream disability theory, which posits that rejecting a disability identity is an unfortunate remainder of the medical model. Within social model theorizing, "oppositional consciousness" (Mansbridge 2001) has become an important strategy for countering the stigma attached to living with a disability. This consciousness will claim a previously subordinated identity as a positive one. People with disabilities are thus encouraged to embrace their disability and find pride in it, rather than denying or downplaying it, or even hoping for a cure. This is not always a simple task in a culture commonly assuming that life with a disability is tragic, unbearable, and probably not worth living. People with disabilities recount stories of being asked how they maintain the courage to face their horrible fates, of being told that, "I would kill myself if I were you," or, of being asked whether they would take a "magic pill" that would make their disability go away. When CBS's *60 Minutes* asked I. King Jordan, the first Deaf President of Gallaudet College, if he would take a pill that would restore his hearing, he responded by asking the interviewer if she would take a pill that would make her a man. He explained that he had never considered this question, and that for him this would be the same as asking a black man to take a "white pill." In the end, Jordan concludes, the interviewer never understood: "she still does not. She still thinks only from her own frame of reference and imagines that not hearing would be a terrible thing" (Jordan 2003, 5).⁶ Jordan's embracing his deafness as part of his identity also points to the importance of having the disability identity project thought about on the same level as race and gender.

The separation of self from disability is thus interpreted as a rejection of a principal part of oneself that disability activism seeks to reclaim as central. As a result, disability scholarship challenges the centrality of the disability in the medical model ("you are your disability and it limits your life") and recenters it in a new way ("disability can be a positive part of your self and

6. Cyndi Jones, former editor of *Mainstream* magazine gave a similar answer to the now infamous magic pill question: "No. It's the same thing as asking a black person would he change the color of his skin" (Shapiro 1993, 14).

should not limit your life"). Embracing one's disability as a central part of the self is also a form of publicly protesting able-ist social norms and pointing to a more inclusive society.

The life stories we read about in *Rights of Inclusion* see disability as a much more problematic force in identity-construction and rights consciousness. Disability studies readers, embracing the ideals of disability culture, might be tempted to conclude that a failure to embrace one's disability as normal or positive, or longing for a nondisabled or "less" disabled self, simply constitutes a form of false consciousness. This, however, would do disservice to the richness of the life stories presented. Rather, the stories tell of a great ambivalence about disability rights, especially when it comes to integrating these rights into narratives about careers and life opportunities. *Rights of Inclusion* demonstrates the ways that the ADA mandate might be celebrated as a symbolic form of liberation and political recognition, but the picture is more complex when it comes to living these rights or integrating them into a sense of self and into everyday life experiences. Moreover, Engel and Munger's observations about disability identity differ in important ways from the normative claim in disability theory about how people with disabilities *should* feel about separating their identities from their disabilities. Theirs, as the authors are eager to point out, is an empirical observation of how and when ADA rights became active in their interviewee's lives.⁷ Differentiating between normative claims and empirical observations is a central aspect of social science research, but for disability studies research methods, as I will discuss in a later section in this essay, this distinction is no longer taken for granted.

In the end, the issue of separation points to a larger question of identity. "Who would I be if I didn't have multiple sclerosis?" asks Nancy Mairs (1996, 9). How do we keep separating our sense of self from our disability when it pervades every aspect of our being? The choice between emphasizing and de-emphasizing aspects of a disability identity is profoundly political but also, as we see in Engel and Munger's life stories, deeply personal and strategic. Some stories show people viewing their disability as one important attribute of their personhood but clearly not as the only one, while others view their personhood almost exclusively in terms of a set of negative images and stereotypes that society has constructed around the concept of disability. As sociolegal scholars interested in the workings of rights, Engel and Munger attempt to tease out the empirical, rather than normative, differences in rights consciousness that they see associated with either approach. The issue of separating self from disability leaves some disability studies scholars to suggest that "it is better to leave questions of identity alone, to avoid having to ask the question, 'Who am I now that I am disabled?' The [medical] model provides an easy and attractive answer to this question: 'You are who you

7. I am grateful to the authors for making this important distinction when they provided commentary on an earlier draft of this essay.

always were. You haven't changed. You remain an individual, a person *with* a disability'" (Michalko 2002, 7).

The Dilemma of Disability Rights: Visible and Invisible Disabilities

The strength of Engel and Munger's life story approach comes to full force when they talk about the complicated effect of ADA employment rights. The ambivalent attitude toward rights is perhaps best described in the different ways that people with visible and invisible disabilities go about advocating for employment accommodations. Borrowing from Martha Minow's (1990) difference dilemma, the authors describe the workings of a "disability dilemma" when it comes to the most contested and litigated aspect of the ADA: employment rights (Engel and Munger 2003, 115–35). This dilemma centers on the conflict between mandating equal opportunities for workers with disabilities by treating them as capable employees, rejecting assumptions about disability meaning the inability to work, and essentially "ignoring" their disabilities, while at the same time recognizing the need for reasonable accommodations of their disabilities to realize the promise of equal opportunities. It is the provision of reasonable accommodations that marks the ADA's departure from the strict antidiscrimination principle inherent in race and gender legislation: rather than just outlawing discrimination, it also mandates the nonstigmatizing recognition of difference. Thus, the ADA recognizes what people with disabilities have known for years: the promise for equal opportunities is meaningless without the guarantee to protect difference.

Yet, as Minow reminds us, both focusing on and ignoring difference risks re-creating it. Engel and Munger uncover the ways that this rings especially true for people with invisible disabilities, for whom rights only play a role in employment when they chose to reveal their disability. The following paragraph succinctly summarizes the dilemma between choosing to reveal or disclose an invisible disability:

Choosing to *reveal* that one has a learning disability may prevent employers and colleagues from misinterpreting its effect on work performance, because symptoms of a learning disability could otherwise be perceived as lack of discipline, aptitude, or intelligence. Yet disclosure may be met with disbelief rather than understanding, and it is far more difficult to explain the nature and effects of a learning disability and the accommodations needed than is the case for many physical disabilities. If, on the other hand Jim *conceals* his disability, he will have no access to legally mandated accommodations that may enable him to perform work successfully. He must assume the entire burden of making adjustments, must obtain assistance without the employer's knowledge or help, and must assume the risk that the effects of his disability will be misinterpreted as professional incompetence (127).

Language and Labels

The attempt to separate the self from the disability has been a central goal in much of disability activism's response to the stigma and negative stereotypes of disability. The idea is to resist the ways that a disability can, in the words of Goffman (1963) "spoil" a person's social identity to the point that society will not see the person behind the cane, the wheelchair, or the diagnosis. The person essentially "becomes" their disability, and language reflects this: they are "autistic," "blind," "deaf," "crippled," "wheelchair-bound," etc. Recognizing the power of language, disability activists have responded by formulating a "people-first" ideology and language to remind the non-disabled (or "temporarily able-bodied") population to "see the person before you see the disability." People First, the pioneering self-advocacy organization of people with developmentally disabilities in Oregon, developed the popular slogan of "label jars not people," arguing that if the label comes before the person, then a large part of who that person is has already been defined.⁸

The most widely used and accepted terminology emerging from people-first language is the term "people with disabilities" rather than "the disabled," or "the handicapped." This change was evident at the highest levels, when the title of federal special education law was changed from "Education of all Handicapped Children Act" to "Individuals with Disabilities Education Act" in 1990, as well as with the ADA's rejection of the term "handicapped" from its model, Section 504 of the 1973 Rehabilitation Act, and subsequent use of people-first language. As a result of the now commonly accepted use of people-first language, the "autistic" becomes "a person with autism," the handicapped child becomes a "child with a disability," and the "spastic" becomes a person with cerebral palsy.⁹

People-first language has been a powerful movement strategy to draw attention to the stigmatizing power of labels, but it has resulted in different terminologies on both sides of the ocean. The shift to people-first language is not universally accepted in the disability community. Disability studies scholars in Great Britain, for example, claim that this move depoliticizes the ways that disability continues to be a source of stigma and discrimination. Rather than placing the person before the disability, they suggest the reverse, to draw attention to the ways that people still are, despite official declarations to the contrary, viewed as products of their disabilities (Linton 1998, 13).¹⁰ British disability theorists Oliver and Barnes (1998) argue that people-first

8. <http://www.open.org/~people1/index.htm> (accessed October 20, 2006).

9. For the best summary of people-first language, see <http://www.disabilityisnatural.com/peoplefirstlanguage.htm> (accessed October 20, 2006).

10. The National Federation of the Blind in the United States rejects people-first language for related reasons (<http://www.blind.net> (accessed October 20, 2006)).

language blurs the distinction between impairment and disability, making the disability the “property” of the person rather than of the society, as the social model dictates. This denies the political nature of living with a disability and draws attention away from social responsibility for mitigating it. They suggest placing the disability before the person as a political statement to show that a disability is something that is “done” to a person rather than something a person “has.”

In either case, disability terminology (What do we call ourselves? What do we ask others to call us?) becomes an important political tool to reclaim a sense of identity and personhood. People-first language refocuses attention from the disability to the person who happens to have it. As such, it echoes Engel and Munger’s discussion of the separation of self from disability: the more people with disabilities can emphasize the “nondisabled” aspect of their identities, the more they are likely to feel entitled to use rights to enable this identity’s full participation in mainstream institutions. In Rod Michalko’s words, “it is small wonder that many of us who are disabled subscribe to the ‘person first’ ideology. We place the common ground of personhood before the not-so-common-one of disability. Choosing personhood over disability emphasizes both the strength of personhood and its separation from the body. As much as we want to repress any memory of the fate of our bodies, we also want to be reminded of just how strong personhood is in the face of this fate. Disability can be our reminder” (2002, 11).

Thus, separating the self from the disability gains access, albeit temporary, to what Zola (1993) has termed “the world of the normal.” And with this access, as we see in the life stories, comes a sense of entitlement to think of oneself as a rights holder. And yet, however this separation resumes a sense of “normalcy,” and its accompanying sense of entitlement to invoke rights, there is the simultaneous attempt at overcoming this division, integrating the two, and accepting disabilities as central part of the self.

ENABLING METHODOLOGIES: NARRATIVE AND PARTICIPATORY RESEARCH

The final part of this essay will consider methodological issues generated by the book’s life narrative approach. The authors’ use of life stories, as well the reflexive nature of their study, has important implications for both sociolegal and disability studies scholarship. I will address these in light of rigorous discussions within the disability literature regarding the methodological implications of the social model. Disability theorists have waged extensive debates on what it means to embrace the social model, both intellectually as well as politically, in the way we conduct and structure our research. Two issues within this debate are echoed in *Rights of Inclusion*: the use of narrative and life stories and the role of the researcher in the research process.

First, the importance of narrative: *Rights of Inclusion* follows a line of sociolegal research on law in everyday life (Sarat and Kearns 1995; Ewick and Silbey 1998) that uses narrative accounts of ordinary citizens to demonstrate the constitutive effects of law. The richly captured and often deeply moving life stories of people with disabilities illustrate law's subtle yet powerful effect on behavior and identity while at the same time highlighting the interviewees' frequent reluctance to think of themselves as rights holders. It is safe to assume that as sociolegal research continues to examine the lives of marginalized groups, the life narrative approach (Engel and Munger 2003, 93) that Engel and Munger advocate will play an increasingly prominent role in sociolegal methodologies. As a discipline we are thus put to task to think more rigorously about how to evaluate these stories and, as I will discuss below, how as researchers and interviewers, we will need to think about our roles in this process.

Disability studies research has tackled similar questions. Initially, the focus was on rejecting the sheer wealth of autobiographies featuring the suffering, coping, or "overcoming" of a disability. In the disability studies community, these stories are commonly viewed as reflections and reinforcements of popular perceptions that life with a disability is tragic, unbearable, and that those who work to overcome the impact of their disabilities should be considered inspirational, if not heroic. As a result, disability theorists using strict interpretations of the social model (primarily those in Great Britain) have cautioned against personal narrative as distracting from the structures of inequality that represent the true disabling mechanism in the lives of people with disabilities. Vic Finkelstein (1996, 11), for example, has charged that personal narratives "dilute" the social model by drawing attention away from the social and barriers that disabled people face as a collectivity. The subjective experience of a disability, he argues, is relevant to the analysis of external social environments, which are to be the focus of analysis. In that vein, the most effective means to engage with emancipatory methodologies are collective agency and the politics of identity rather than narratives or life stories.

This argument has been challenged in disability studies on both sides of the Atlantic, leading to a renewed interest in narrative and autobiography as a transformative tool. The initial challenge came from feminist scholars pointing to an undertheorization of impairment as part of larger problems with social model theorizing. As discussed earlier in this essay, the social model, as first theorized by British scholars, relies on a binary opposition between the terms *impairment*, the functional limitation within an individual caused by physical or mental impairment, and *disability*, the social consequence of exclusion or discrimination based impairment. Privileging the theorizing of the social production of disability has been both a political and theoretical choice to counter the prevalence of the medical model, but it has prompted feminist scholars Jenny Morris (1991), Susan Wendell (1996),

and others to call for more inclusive theorizing of the disability experience that gives more weight to personal experience with impairment. Similarly, Bill Hughes and Kevin Paterson have pointed out that although the impairment-disability distinction demedicalizes disability, it renders the impaired body the exclusive jurisdiction of medical interpretation (Hughes and Paterson 1997, 330). This division is akin to the sex-gender dichotomy in feminism, argues theorist Shelley Tremain, in that it has rendered impairment—as the embodied experience of disability—as some “objective, transhistorical and transcultural entity which biomedicine accurately represents” (Tremain 2002, 34). She suggests use of Foucault’s historical approach to show that this “allegedly ‘real’ entity is in fact a historically contingent effect of modern power” (34). Tremain’s analysis of the social model’s theoretical limitations is part of a larger wrestling with the legacy of social model by feminist and post-modern disability scholars (Corker and Shakespeare 2002). As witnessed by these debates, the theoretical challenges to social model have extended to a critical assessment of the research methodologies once dictated by the social model.

A return to narrative, then, lies at the heart of disability theory’s attempt at creating an “embodied” theory of disability and renewing social model theorizing to include personal experiences. Scholars of literature and the humanities, ever growing in disability studies circles, have also pointed to a need to reclaim narrative as a counterdiscursive tool (Couser 2002). G. Thomas Couser takes seriously the dangers of sentimentalism articulated by Lennard Davis, “by narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story” (Davis 1995, 4). Similarly, Ann Finger talks about the risks of writing her life story, “it is my old fear come true: that it you talk about the pain, people will say, see, it isn’t worth it” (Finger 1990, 33). Nonetheless, Couser insists on ways to use narrative and autobiography to “deconstruct the often seductive . . . popular portrayals of disability” (Couser 2002, 110).

Scholars of disability policy have also reclaimed the importance of narrative, albeit for different reasons. Within disability policy studies, narratives and oral histories are seen as “important tools in the process of political empowerment and in the effort to redefine the cultural meaning of disability” (Hirsch 2000, 428). Engel and Munger’s life stories offer a productive move toward this process. Their attention to critical theories of rights and consciousness will allow disability studies scholarship to reconsider the role of rights and identity, especially when the question of disability rights has been posed with a critical eye. Damon Young and Ruth Quibell, for example, explore “why rights are never enough” by criticizing the atomizing effect of rights discourse, something that is well familiar to readers of this journal. The path to justice, they argue, is not paved with rights but with life narratives that will allow people to truly understand each other. Understanding intellectual

disability, for example, is not a project to “get into the head of those less ‘able,’” but to use a larger understanding of culture—something that rights fail to do—to understand “where they are coming from” (Young and Quibell 2000, 759). Thus, within a life story approach, “each person within a culture can see himself or herself as an unfinished story, coming to terms with the stories of others, and attempting to ascertain the ways in which such stories intertwine” (Young and Quibell 2000, 759). This wide variety of disability studies authors I have cited all point to the need to recapture narrative as an important methodology in the project of understanding the intersections of rights, disability, and identity.

Participatory Research Methodologies

The theoretical challenges to the social model pertain not only to the use of narrative but also to larger methodological issues. Thus, my second methodological point has to do with the reflexive nature of the study: a selected group of participants were asked to review the authors’ account of their lives and then invited to write comments or criticisms on the author’s interpretations; the comments were incorporated in the book, appearing in italics. Engel and Munger wanted to expand the role of the interviewees to highlight the “dialogic quality of ethnographic fieldwork” (Engel and Munger 2003, 9) and to underscore their argument that “life stories are not fixed and forever unchanging, but are constantly questioned, revised, and reinterpreted by the narrators themselves as well as the researchers that record them” (9).

By highlighting the role of the researcher in narrative production, and by letting their research subjects “talk back,” Engel and Munger are drawing attention to power relations in research, something that has been widely discussed in disability studies scholarship and that represents a larger move in qualitative methods employed by sociological and anthropological research (Whyte 1991; Hatch and Wisniewski 1995; Smith 1999). Studies using participant observation methodologies or ethnographies have drawn attention to some of the ethical tensions inherent in fieldwork, especially when researching marginalized or disempowered communities. This shift in methods prompts researchers to consider their position as researcher in relation to their subject, and the ways they may impact the communities they are researching (Schneider 2002), and how their research subjects may react to the ways they are portrayed (Tobin and Davidson 1990). Especially feminist methodologies have drawn attention to power relations in interviewing and caution about potential appropriation of the “other” in qualitative research (Opie 1992; Wolf 1996).

An instructive example here is Verta Taylor’s (1998) reflections on how her use of feminist epistemology and methodology shaped her study of

postpartum depression self-help movements. She asks important questions that apply equally to methodologies used in disability research:

In studying postpartum illness and the social movement that emerged to address this problem, my goal initially was to use research procedures that fit the feminist goal of challenging gender inequality and empowering women and other marginal groups. Ultimately, however, the purpose of social science research is to explain, and thereby to solve, social problems. If, as feminists hold, women experience a series of erasures and distortions owing to their structural location that can become epistemologically constitutive, how do feminist methods allow us to see features of the world that remain invisible or secondary to conventional research? What new points were incorporated into my thinking as a result of the feminist method? How was my understanding of social movements transformed? (Taylor 1998, 374)

In the end, Taylor argues that a feminist research approach—which includes reflexivity, combining scholarship with activism, and an active participation of her research subjects in every stage of research—allowed her to not only recognize the gendering of social movement processes and theory but also to question the feminist dismissal of self-help as a simple upholder of the gender status quo (Taylor 1998, 375).

Drawing attention to the politics of location, these methods serve as an important reminder that in our role as researchers, we use the lives of others not only to generate scholarship but also to promote our own research and ultimately our own careers. This kind of inquiry has become quite common in “participatory” or “emancipatory” research in disability studies. Participatory research, known by the acronym PAR (“participatory action research”) in U.S. disability studies, mandates an active role for people with disabilities in designing and conducting disability research. It is designed to empower people through the process of constructing and using their own knowledge to increase the relevance of the research process. In the United States, participatory research has become well established in government-funded research: the amendments of the Rehabilitation Act of 1992 promote PAR by establishing principles of consumer involvement in research. The Department of Education’s National Institute of Disability and Rehabilitation Research (NIDRR) has also promoted the role of PAR in disability and rehabilitation research (Balcazar 1998). It is safe to say that PAR has become institutionalized in government sponsored disability research.

In Great Britain, the equivalent term is emancipatory research, which has a more explicitly political mandate. Emancipatory research requires that disabled people exert control over both the social and the material relations of research production and thereby transform traditional power structures

(Barnes and Mercer 1997). It has its roots in the Marxist dictum that research should be about changing the world, not simply describing it. As such, it is part of contemporary critical inquiry that challenges notions of objectivity and neutrality on the grounds that all knowledge is socially constructed and culturally relative. In contrast to participatory research in the United States, which focuses primarily on the participation of research subjects in the research process, emancipatory research characterizes itself by empowerment and reciprocity. It demands that social research be motivated by a desire to work toward the political and social emancipation of the subjects of this research (Zarb 1992). British theorist Michael Oliver, a vocal critic of U.S. disability research, has criticized participatory research for leaving the social and material relations of research “untheorized and untouched” (Oliver 1997, 24). This criticism is in line with the larger differentiation between the more self-consciously politically left British discipline and its American counterpart. The disability studies literature in general tends to conflate the two methodological approaches, suggesting that the differences between the two might be more in emphasis, rather than in kind (Northway 2000).

The differences between the two approaches are less important than the potential applications they suggest for sociolegal scholarship. Both approaches grew out of dissatisfaction with traditional disability research under the medical model that tended to disregard or even violate the experiences and needs of its intended beneficiaries. This was especially troubling to activists that saw rehabilitation and special education research being conducted to promote policy reforms, which did not include the voices of people with disabilities or aid in the improvement of their lives. As a result, people with disabilities have come to view disability research not as a tool to counter the oppression they face but rather as a means by which it is being perpetuated (Vernon 1997). In a commonly cited essay launching this critique, disability researchers are depicted as “parasites” on the lives of their research subjects (Stone and Priestley 1996).

To address this situation, both participatory and emancipatory research demands the recognition of disabled people as experts of their own experiences and their inclusion into all stages of research production—from the creation of research questions, to choices of methodologies, interpretation, and the writing of the final report. Traditional positivistic research methodologies traditionally cast the researcher in the role of expert and implicitly devalue the knowledge and experience of the research subjects. People with disabilities were passive subjects of study, deprived of any input into the research process other than responding to questions. The new paradigms stress the active role and equal participation of people with disabilities and bases research on their lived experiences and needs. This has become especially important for applied research designed to generate or reform disability policy. Here, the inclusion of stakeholders is of utmost importance to ensure that policy addresses real

needs and contributes to the improvement of social and material conditions of the stakeholders.¹¹

Promises and Limitations of Participatory Research

Just as the theoretical shift from the medical to the social model emphasized a shift from viewing people with disabilities as objects of medicine to political, rights-bearing subjects, we now see a methodological shift from viewing them as research subjects to equal participants. *Rights of Inclusion* is an example of this shift in both substance and method. Along with my discussion of the book, I will use three examples from traditional disability research to illustrate some of the promises and limitations of participatory research.

The ethical and moral drive fueling participatory action research is particularly applicable for research on vulnerable populations normally protected by university review boards. As mentioned earlier in this essay, PAR has become the default choice for applied disability research, because it draws attention to vulnerabilities and potentials for exploitation or misappropriation. This holds especially true for research on and about people with intellectual disabilities (Sample 1996; Ward and Trigler 2001). The field's preoccupation with methodological questions has prompted a lively debate surrounding the uses (Sample 1996; Santeria et al. 1998), and misuses (Danieli and Woodhams 2005) of participatory research with, by, and about people with disabilities. There is a strong sense of self-consciousness regarding choices of methodologies in the field. Consider, as an example, a recent British study of disabled peoples' experiences and opinions on being the "subjects" of disability research (Duckett and Pratt 2001). This kind of inquiry points to the fact that in its strictest application, emancipatory research should only be done on subjects that the researchers deem oppressed and in need of emancipation. Part of the responsibility of the researcher is to select marginalized groups

11. Disability research is not the only prominent site for emancipatory or participatory action methodologies. There are interesting parallels in research on the formation of homelessness identity and activism and the connections between research on stigmatized identities and social policy. Studying the ways that people who are homeless adopt or reject the homeless label invite comparisons to the ways Engel and Munger show their research subjects engaging with disability identities. As an example, consider Snow and Anderson's (1993) ethnographic research on homelessness that highlights the use of "identity talk" to "salvage the self." Their work distinguishes identity practices based on the length of time somebody has been homeless, which speaks to the importance of time in the lifecycle that a person with disabilities first experiences disability. This distinction in identity practices has important implications for the generation of social policy. In a participant observation study on the generation of homelessness identities, for example, Alice Farrington and Peter Robinson conclude that earlier stages of homelessness, in which identification with homelessness is low, require different policies than policies for those homeless whose positive identities have become more entrenched in homelessness. (I am grateful to Lynn Jones for pointing me to this literature.)

and then apply the tools of research toward their emancipation, as well as certifying that this is something the subjects actually want.

The examples from British and American disability research I have selected will illustrate the ways researchers have grappled with these requirements. The British example demonstrates the implications of a political commitment to emancipatory research in which “the political standpoint of the researcher is tied to political action in challenging oppression and facilitating the self-empowerment of the people” (Stone and Priestley 1996, 703). Prominent British scholar Mark Priestley recounts his early experiences with emancipatory research while in graduate school. His story illustrates the struggle to realize what he considers the radical agenda of emancipatory research while still producing an “academically credible piece of disability research” (Priestley 1997, 89). For Priestley, this meant giving up control of the research question from the very beginning. He admits that this made him vulnerable and caused him to question the wisdom of this choice at numerous occasions. But, he suggests that, “my hope was that by engaging with the participants at the very outset we could work together on defining a research proposal over which they could claim ownership” (Priestley 1997, 94). He decided to create a contractual obligation that commissioned him to do his research for the two groups he was investigating, effectively putting them in charge over the research agenda. When, for example, Priestley was ready to publish his initial research findings, heeding the pressure to publish in academic journals as part of his requirements toward his scholarly self, he realized that his material was politically sensitive and not appropriate for wide dissemination at the time. Here was a moment where his academic self and political self came into conflict.

To devolve control over the dissemination of research findings is to accept that there may well be constraints on the researcher’s ability to publish. I am not necessarily advocating the participants’ right to “veto” over research outputs but I do believe that a sincere commitment to collective responsibility requires us to reject our absolute privilege to “independence” (Priestley 1997, 100).

Priestley’s commitment to emancipatory research design also dictated his approach to contacting potential interview subjects. For example, he used a three-stage strategy for interviewing. In contacting subjects, he drafted a set of potential interview questions, a time line for the interviews, a statement of good practice outlining what participants could expect from their contact with him, and a detailed outline of the purpose of his research and his role as a researcher. All of this painstaking detail was to ensure that participants could make informed decisions before, during, and after the interviews. Once the interviews were conducted, participants were given copies of the draft report for comment and amendment. The purpose here was not only to

receive information from service users but, as the emancipatory paradigm demands, empower participants to become more active and critical consumers of social services. "The intention was to encourage the participants to use the interviews not only to give voice to their views and experiences but also to facilitate their greater influence over the development of [the group's] service provision" (Priestley 1997, 102).

Ultimately, the relationship worked in the best interests for both contractual partners. Priestley was able to gain governmental funding for his project (albeit only after taking out the term, emancipatory, from his application) and fulfill his scholarly goals of publishing and receiving his degree. The disability service groups were able to use his research skills and reports to influence local policymakers and engage in developmental and advocacy work, something they would not have achieved to this degree on their own. In the end, however, Priestley concludes that the research project was "more personally empowering to me than to anybody else."

In comparison to Priestley's self-consciousness toward his roles and responsibilities, consider the more practical applications of participatory research by U.S. disability researchers Fabricio Balcazar and Christopher Keys. They locate the goals of PAR in the consumerism, self-help, and civil rights movements and structure their research agendas accordingly (Balcazar 1998). One of the prominent examples of their use of PAR is in their study of disability rights in Latino communities, in which they sought ways to help Latinos with disabilities from the Chicago area increase ADA compliance in their communities (Balcazar, Keys, and Suarez-Balcazar 2001). The principles of PAR allowed them to generate a more accurate, contextual and authentic analysis of the social realities facing the people they were researching. In a related research project, they used PAR to help Latino youths with disabilities, who had dropped out of school, return to school or find jobs they could keep (Balcazar and Keys 1997). Here, too, the direct involvements of youths with disabilities led to adaptations to the proposed interventions, which in turn resulted in a much more comprehensive approach that was necessary to address the multiple needs of their research subjects.

The final example focuses on the question of accessibility in participatory research. If research is meant to aid in the emancipation of people with disabilities, how can it be made accessible to people unfamiliar with academic language or jargon? Disability scholars have suggested that writing to an expanded audience for our publications that includes both academics and community members will force a new set of awareness about language. Jackie Rodgers (1999) tells of her experiences with emancipatory methodologies in her research involving people with learning disabilities. She says,

I have a commitment to making the findings of my research accessible to people with learning disabilities. I began the study thinking that there are some ideas which are too conceptually sophisticated to simplify, and

therefore would inevitably be inaccessible to people with learning difficulties. My experience has led me to believe that many apparently complex ideas can be expressed plainly and understood by many people with learning difficulties. Furthermore, this process of presenting ideas in a way which is easier for most people to understand is intellectually healthy, making the author very clear about what they are saying (Rodgers 1999, 431).

The three examples I have cited offer illustrations of what a commitment to self-reflexive research might look like and also suggest ways in which this commitment can give rise to unintended problems. What happens, for example, when research subjects do not accept the premises of the social model in the understanding of their own experiences with disability? Or if they resent being considered research subjects in need of emancipation? The privileging of the social model, as mandated by the emancipatory project, would suggest this as a form of false consciousness. As I argued earlier, Engel and Munger are careful to avoid the issue of false consciousness by taking seriously their respondents' unease with rights claims under the ADA, choosing instead to "give great weight to the opinions of the rights holders themselves" (Engel and Munger 2003, 97). Moreover, what *Rights of Inclusion* shows so exquisitely is that people's conflicting views of disability rights is warranted precisely because the effect of these rights on their lives is so complicated. Here is a complexity, forming the center of the book's analysis on disability rights that could be misinterpreted or sidestepped by traditional participatory action methods urging personal empowerment and political change.

Another potential limitation of participatory or emancipatory research is suggested by the fact that PAR substitutes small groups of research subjects for the group as a whole. This resonates with critiques of the use of narrative and life stories cited earlier in this essay: to what degree do we lose important generalizations about social conditions and experiences shared by of people with disabilities as a collective or, in the words of the ADA, as a "concrete and insular minority," rather than as unrelated individuals? As Danieli and Woodhams (2005) suggest in their critical essay, an overly dogmatic adherence to emancipatory research, as they see in contemporary British disability research, can ironically "constitute an exercise of power that potentially marginalises some voices and potentially oppresses some disabled people and researchers." The authors conclude that ultimately, "rather than prescribe emancipatory research as the only legitimate methodology for disability research, disability writers should, as feminists have in researching gender, adopt a more pluralist and eclectic approach to theorising and researching disability" (517).

Finally, there is the question of the degree to which a researcher's position in the academy compromises a commitment to PAR. In his essay appropriately titled "are academics irrelevant?," Randy Stoecker (1999, 842) wonders, "if [participatory research] is really revolutionary, and if academics

are relatively privileged members of society, do we help or hurt the cause?" He outlines three roles for academics dedicated to a participatory research process that includes a commitment to social change: the researcher as animator, as consultant, or as collaborator. Determining how the academic will fit into a project requires asking three questions: What is the project trying to accomplish? What are the academic's skills? And how much participation does the community need or want? Stoecker's is an important reminder to be mindful of structural impediments to PAR emanating from our roles as researchers, as in the academy as well as in the field, while at the same time thinking creatively about ways to make our research matter.

This should lead us to wonder to what degree disability studies researchers can—or should—maintain a critical distance from disability politics and activism to examine its successes, failures, and contradictions. Disability researchers who feel political allegiance to the communities they study can benefit from a tremendous set of methodological resources in the PAR and emancipatory literatures. At the same time, disability researchers still require a critical distance to interpret the social world of others. As my examples have shown, a political commitment to PAR or emancipatory research is useful and appropriate for applied research, but what about research that is primarily interested in generating theory?

Methodological Bridges

This is not to suggest that theoretical rigor and participatory action are mutually exclusive goals. Engel and Munger's attention to narratives in *Rights of Inclusion* certainly is a step in that direction. Participatory research can and should play an important role in shaping methodologies, even when—as for Engel and Munger—research is primarily designed to generate theory. In that sense, *Rights of Inclusion* functions as an important bridge between disciplines. The principles of PAR can bring depth and complexity to sociolegal scholarship of social movements and marginalized groups by prompting researchers to reflect on their political allegiances to the organizations they are researching, the ways they present themselves, and their research agenda to their subjects and the impact of their research on the political, economic, and social realities of these organizations, groups, or individuals. PAR also suggests innovative ways to interweave text, narratives, and fieldwork notes, something we can see in Barbara Yngvesson's (1997) study of open adoptions. Yngvesson inserts personal experiences into their articles, becoming both researcher and subject, acknowledging and reflecting on their positioning *vis-à-vis* her subjects as well as her topic.

Many of the principles inherent in participatory research are reflected in a concern within sociolegal scholars toward social justice or "engaged" research. A common theme of presidential addresses for the Law and Society

Association (LSA) (Joel Handler 1992; Sally Merry 1995; Kitty Calavita 2002, just to list a few) has been research that is relevant for broad progressive change. Sally Merry (1995, 12), for example, asked “has recent law and society research abandoned its historic concern for social justice and progressive politics and replaced it with . . . work that focuses on the mundane, the arcane, and the politically irrelevant?” Similarly, Kitty Calavita (2002, 11) invites sociolegal scholars to become “public intellectuals” and suggests that, “if the engaged researcher is interested in social justice and asks big—that is to say, important—questions, the public intellectual, in her concern for social justice and the democratic process, is one who asks those big questions in public, and in doing so stimulates the public debate and advances the discourse.” Both Engel and Munger also emphasized a critical inquiry into social activism and researcher-subject relations in their LSA presidential addresses. David Engel (1999, 5) explains that, “Whatever approach we use, we hope that our interviewees will act as sociologists of everyday life, not just as people who are observed, but as observers of their own world.” This commitment certainly resonates in the stories we read about in *Rights of Inclusion*, but it leaves readers from disability studies looking for a more self-conscious examination of the impact of our methods and methodological divides. As the disability category becomes more incorporated into sociolegal thinking about rights and identity, the disability studies experience with participatory and emancipatory methodologies provides a vital addition to sociolegal thinking about how to do research “on” and “with” real people’s lives, consciousness, and experiences with injustice. In that sense, reaching out and “making connections” across different methodologies and disciplines must continue to lie at the heart of law and society research.¹²

Disability and Sociolegal Studies in Conversation

There is much that disability studies and law and society scholarship have to say to each other, and *Rights of Inclusion* offers a productive starting point for this conversation. Engel and Munger’s posing of the identity question challenges the very foundation of the social model: the binary opposition between impairment and disability. Disability theorists have launched sophisticated projects recognizing ways that the social model has failed to address adequately the fundamental issue of bodily agency and challenging the ways it represents the disabled body “as a passive recipient of social forces” (Paterson and Hughes 1999). The life stories in *Rights of Inclusion* provide ample background and illustration of how people with disabilities struggle with the

12. “Making Connections Across Disciplines, Theories and Methods” was the theme of the 1999 Law and Society Association’s annual meeting at which David Engel delivered his presidential address.

social model and how life with a disability cannot easily be separated into a personal and a social reality.

Life stories of experiences with disability, rights, and identity also point to ways that thinking about disability rights can have transformative potential beyond disciplinary boundaries. Thinking about disability discrimination at the workplace, for example, illuminates taken-for-granted assumptions about workplace norms, such as working hours, qualifications, and spaces. What elements in a job description, for example, are truly the “essential functions” of a job and which ones arise from tradition, habit, and comfort of the known? The accommodations given to workers with disabilities—flexible hours, time to rest, or working at home—would make for a more humane workplace if applied to every one. As Engel and Munger remind us, “the drafters of the ADA envisioned a radical transformation of the culture of work, requiring workplaces to adapt to the individual capacities of qualified workers rather than the reverse” (Engel and Munger 2003, 120). Similar arguments apply to university teaching and learning. Rather than limiting accommodations such as note takers, multidimensional learning, extended time on tests, or flexible assignment schedules to those students who are legally entitled to them based on their disability status, why not design a classroom experience that accommodates all types of learning styles? Accommodations made available to all students would lose their stigma and make for a better learning experience for all students. Moreover, wouldn’t the challenge of teaching a more diverse student body inspire all of us educators to become more creative and innovative in our teaching methodologies?¹³

Arguments like these are part of a larger project toward a “universality” of disability policy that would transcend the equal rights/special needs dichotomy (Zola 1989). Thinking about disability rights and the ADA can inspire both sociolegal and disability scholarship to ponder larger assumptions about how we work, how we teach and learn, and the role of rights in both. As Simi Linton, with whom I led off this essay, concludes,

Hidden and disregarded for too long, we are demanding not only rights and equal opportunity but . . . that the academy take on the nettlesome question of why we’ve been sequestered in the first place. . . . [I]n disregarding disability as subject matter, disabled people as subjects, and disabled people’s subjectivity, academics have been complicit in that confinement. Yet, each of these elements, worked through the curriculum, can serve not only to liberate people but to liberate thought (Linton 1998, 185).

13. This concept is called “universal design for instruction” that is increasingly championed in secondary and postsecondary settings. The Office of Postsecondary Education within the Federal Department of Education has been sponsoring grants to universities to promote “innovative and sustainable teaching methods and strategies to ensure that students with disabilities receive a quality higher education.” For an example of such a program at the University of Hawai‘i, see <http://www.ist.hawaii.edu> (accessed October 16, 2006).

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