

H-Net Reviews

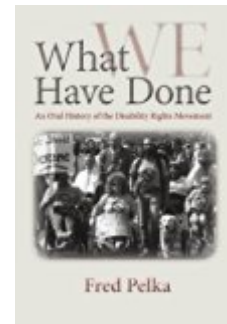
in the Humanities & Social Sciences

Fred Pelka. *What We Have Done: An Oral History of the Disability Rights Movement*. Amherst: University of Massachusetts Press, 2012. 592 pp. \$29.95 (paper), ISBN 978-1-55849-919-5; \$90.00 (cloth), ISBN 978-1-55849-918-8.

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A Treasure Trove of Oral Histories

In *What We Have Done*, Fred Pelka delivers an outstanding collection of oral histories focused on disability rights activism during the decades leading up to and including the passage of the Americans with Disabilities Act (ADA). He draws from three sources: the oral histories compiled by the Oral History Office of the Bancroft Library at the University of California at Berkeley as part of the Disability Rights Independent Living Movement national research and documentation project; the interviews conducted by the Disability Rights Education and Defense Fund in 1999-2000 to mark the tenth anniversary of the passage of the ADA; and interviews conducted by himself. In total, *What We Have Done* contains narratives from seventy-four individuals who have been active in the disability rights movement. To create some historical coherence regarding the disability rights movement, Pelka positions the material by event or topic in loose chronological order, which means that some of the narratives are broken into sections. In doing so, he is able to organize the narratives in a way that roughly reveals the workings of the disability rights movement, its key events, and the primary constituencies and coalitions, while still largely retaining the integrity of the oral histories. He also provides chapter introductions which offer short historical synopses in order to situate the oral histories for the reader.

Pelka is very clear about his purpose: “to recount the political struggle for disability rights” through first-person accounts of people with disabilities and their al-

lies (p. ix). He is very cognizant of the strengths and limitations of this approach. To focus on its strengths first: the reader is provided with in-depth narratives of key individuals, through which we can gain insight to their perspectives, motivations, and actions. These personal narratives are compelling and easy to read, even for someone previously unfamiliar with the disability rights movement. Because the narratives retain much of their original form, they can be analyzed over and over again for a variety of insights. Pelka’s collection is thoughtful in its representation of leaders and activists. The reader hears from well-known heroes such as Judy Heumann, Ed Roberts, and Justin Dart, as well as from leaders among psychiatric survivors, self-advocates, the Deaf President Now campaign, and the disability press. Pelka also strives to provide diverse voices in terms of gender, race and ethnicity, sexual orientation, class, and educational backgrounds so that the reader can consider how these factors shaped the movement.

There are some inherent trade-offs given his approach, including that the chronological account is very loose, with stories overlapping in events. Due to the multiplicity of narratives, the book lacks a dominant historical narrative and argument that provides an overarching explanatory account of the history of the movement. For example, the institutionalization of people with disabilities is showcased early in the volume. Through these stories we hear of the impact of institutionalization on the lives of survivors and of specific efforts toward de-

institutionalization. The activists' stories are fascinating, but together they do not comprehensively or concisely tell the story of the growth of institutions, deinstitutionalization, or the continued presence of institutions in America. Pelka's central goal is to put forth first-person narratives, rather than to lay out a clear explanatory account of macro social changes. However, given that there are already published historical accounts of the disability rights movement with clear chronicity and broad explanations for macro social change, Pelka's focus on first-person narratives offers an important complement to this growing body of scholarship.[1]

Pelka also shies away from thematic or content analysis of the first-person narratives, preferring to let them stand for themselves. This decision is at times frustrating because most potential themes are never elaborated and connections across the narratives remain largely unmade. While this can be disappointing, it is also a tremendous opportunity for readers because they are able to discover for themselves what gems lie within the narratives. To offer a few examples of the themes that one can uncover (but that Pelka does not discuss explicitly), I personally enjoyed exploring the following themes: the complexity of individual biography, the intersections of identities and movements, and the complex strategies of the movement. I will discuss each of these themes briefly as a way to reveal some of the narrative content and its implications.

First-person accounts are particularly adept at revealing the complexity of individual biography, and here we hear many of the activists tell of a growing consciousness that transformed their perspective, identity, and actions. Part of the growing consciousness is the reframing of exclusion from a personal trouble to the public injustice of discrimination. For example, Mary Lou Breslin recalls as a young adult being hassled by the management of her local movie theater about whether she would be admitted and where she could sit. When her friend described the situation as discrimination, she did not agree. She said to him, "What are you talking about? That's stuff that happens to black people. It's not applicable to me." Reflecting on that moment, Breslin stated, "It was a very insightful moment that came and went, and twenty years later I figured out that he was right. I didn't get the analogy—I understood discrimination in race, I even understood it pretty much in gender. I didn't get it in disability. I just didn't get that it was the same thing" (p. 67). Some stories also consider the role of the narrator in perpetuating inequality. Justin Dart, for example, initially used disability events as a tool for corporate promotion and

image building. Confronted with the juxtaposition of his own privilege and the oppression of the disabled people he planned to use for corporate promotion, he realized, "This is evil. I have encountered evil and *I am part of it*. I am killing these kids just about as much as the people who are running this atrocious fraud of an institution, this concentration camp. And remember they are raising money for this place under the guise that it is an institution for children. And I am here using this atrocity as a photo op" (p. 173). These stories showcase the evolution of identity that contributes to one's activism.

Related to identity, Pelka's attention to diversity allows the reader to consider how, why, and when the disability rights movement intersected with other rights movements and identities. Corbett O'Toole, for example, recalls the support of the Black Panthers in the HEW (U.S. Department of Health, Education, and Welfare) demonstrations. Karen Thompson shares a fascinating account of the battle to return to her partner, Sharon Kowalski, after a disabling accident. Sharon's parents fought to have her placed in a nursing home, and Karen recalls that the disability rights movement was hesitant to get involved with what they saw at first as a gay-rights issue. "We were told, when we finally sat down with national leaders of the disability community, with the women's community, with the lesbian/gay/bisexual/transgender community, that it was the first time that they'd ever all come together and rallied around one case" (p. 371). Other stories tell of the deep divides that separated communities. For example, of the prejudice within the disability rights movement toward people with psychiatric labels, Cyndi Jones wisely said, "just like you bring people along who are disabled but not really in the movement, you sometimes have to bring the movement along too" (p. 233). Pelka does not offer us an analysis of intersecting identities, but provides a rich array of narratives through which to consider this issue.

Readers are also treated to stories that illuminate a broad range of strategies for social change. We hear about famous events such as section 504 demonstrations, the rise of the independent living movement, and the Deaf President Now campaign. Moreover, readers are exposed to many other, lesser known examples of social activism, often performed by people trying to create change in their local communities. For example, Ray Uzeta recalls his efforts in San Francisco to establish a mandate for curb cuts along Market Street when this street was undergoing reconstruction. After that victory, he helped establish a larger coalition to remove architectural barriers throughout the city. As another example,

Michael Auberger, co-founder of ADAPT, described early protests against McDonald's due to their inaccessibility, and states, "And it all started from the want of a Big Mac, from one guy wanting a Big Mac and not being able to get one" (p. 367). These stories support the belief that people can change the world, sometimes one burger or one street at a time, and inspire our imagination about the role that we too might play.

The primary contribution of *What We Have Done* is as a terrific compilation of narratives that detail the complexity of the disability rights movement from many perspectives. The narratives also serve as a reference source for scholars interested in exploring various themes. Historians, sociologists, psychologists, linguists, and others will certainly find material of interest within these rich

accounts. While I explored the theme discussed above, in this rich treasure trove of narratives, there is certainly something for everyone.

Note

[1]. See, for example, Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2011); Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Random House, 1993); Henri-Jacques Stiker, *A History of Disability*, trans. William Sayers (Ann Arbor: University of Michigan Press, 1999); and Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality* (Washington, DC: Georgetown University Press, 2003).

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