## H-Net Reviews in the Humanities & Social Sciences

**Judith E. Heumann.** *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist.* Boston: Beacon Press, 2020. 240 pp. \$25.95, cloth, ISBN 978-0-8070-1929-0.

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Judy Heumann's memoir, Being Heumann, recounts her journey from polio patient to prominent disability activist. While it follows her life from its beginnings in Brooklyn, the book focuses on three distinct periods in her development as an activist. The first section details her early years in Brooklyn, her encounter with the polio virus and her recovery, and her efforts to get an education and find employment as a disabled polio survivor. Here she also recalls her initial forays into disability activism, inspired by her frustrations at being rejected as a teacher because she used a wheelchair. In the second section, she details her move to Berkeley, California, in 1977 to work with Ed Roberts (1939-95) at the nation's first center for independent living. This section focuses on the demonstrations to force the implementation of the Section 504 federal regulations that prohibited discrimination against individuals with disabilities in an institution or facility receiving federal funding. We get a good sense of the planning, determination, and luck that went into the success of the long sit-in at the federal offices in San Francisco that eventually led the secretary of health, education, and welfare (HEW) to sign the regulations, thus implementing them. The third section recounts her increased disability activism, first on a national scale and then on a world stage. It also covers her move into government and other institutions where she continued to push for change from the inside instead of from the streets.

Heumann begins her account with her childhood in Brooklyn, where she had polio at age three in 1949. She opens her memoir in 1953, when she was six and joined her friends in play from her wheelchair. She stresses how her friends accommodated her disability and incorporated Heumann in their play. She did not develop a sense of difference until September of that year when her friends went off to school and she did not. She was not permitted to attend because children in wheelchairs were "fire hazards." Her mother fought to gain entrance for her daughter, but eventually had to settle for a year of home instruction. She also recalls her growing sense of being different. Although her friends seem to have treated her normally, other children did not. That, along with the school situation, fed her sense of difference.

Her mother eventually succeeded in getting her daughter into a school, though it turned out to be a school specifically for children with disabilities. Though excited to finally be going to school in fourth grade, Heumann was disappointed to discover that the school was not an ordinary fourth grade, but a classroom for a wide variety of disabilities, grades, and ages. It was not at all what she expected or wanted. No one, she writes, really expected the special education students to learn.

One valuable lesson was her introduction to "disability culture": "a culture that has learned to value the humanity in all people, without dismissing anyone for looking, thinking, believing, or acting differently" (p. 23). She also recalls her visits to summer camp for children with disabilities, where they were all "drunk on the freedom of not feeling like a burden, a feeling that was a constant companion in our lives outside of camp" (p. 25). On so many occasions, she and other disabled children of that era "accepted that our inclusion was dependent on someone else being 'nice'" (p. 26). Camp, she felt, "was what it would feel like if society included us" (p. 27).

Going to a public high school was Heumann's "sudden immersion in the tidal wave of nondisabled kids," and it initially "unnerved" her (p. 30). She experienced the loneliness of being disabled in an able-bodied world: being ignored and facing lowered expectations for success as well as assumptions that she would not date or ever marry. Following graduation, Heumann attended Long Island University, twenty minutes from her home. Here she discovered that even agencies dedicated to assisting students with disabilities operated with damaging preconceptions. The Office of Vocational Rehabilitation would not support anyone studying to be a teacher because they did not consider that a realistic career for someone with a disability. As a result, she chose speech therapy as a major and developed an alternative route to becoming a teacher. Heumann recounts the challenges of living on her own in a dorm for the first time, finding the kind of assistance she required to meet her daily needs, and making friends. She recalls that the exclusion she experienced at college "especially at the level and frequency at which I experienced it, is traumatic" and painful (p. 41). She and the other disabled students developed a new awareness: "We were beginning to see our lack of access as a problem with society, rather than our individual problem" (p. 42). While in college Heumann was elected to student government and became active in antiwar campaigns against the Vietnam War.

Heumann's next challenge came as she fought to acquire the credentials she needed to be certified as a public school teacher. She recounts in some detail her struggles with the Board of Education, the failure of the American Civil Liberties Union to take her case, and her decision to sue the Board of Education. She also turned to the press, especially the The New York Times, which came to her support. The publicity led to a lawyer and growing support for her cause locally and nationally. It was her first public challenge to the expectations, laws, and regulations that had for so long limited and restricted the lives of men and women with disabilities. Following a court hearing, the Board of Education settled out of court and granted her the credentials she had earned. Her next challenge was to find a job since almost all schools were reluctant to hire her. Finally, her old school with the special education class hired her to teach both disabled and nondisabled students.

Heumann's experience in college and her fight with the Board of Education inspired her to create Disabled in Action in 1970, one of the first disability rights organizations. Disabled in Action led one of the first protests in support of Section 504 of the 1972 Rehabilitation Act. Her activism in New York eventually led to a call from Ed Roberts in Berkeley inviting her to work with him at the Center for Independent Living. After some hesitation, she agreed and moved to Berkeley in 1977.

The second section of the book describes her work with Roberts in Berkeley, her time in Washington as a senatorial aid, and her participation in the demonstrations that eventually led to Joseph Califano, the secretary of HEW, signing the Section 504 regulations implementing the provision. Heumann describes in significant detail the planning that went into the demonstration and the unplanned ways in which it eventually became a long sit-in at the HEW offices in San Francisco. She gives a vivid portrait of what it was like to be a par-

ticipant in the sit-in, the intense debates about how to proceed, the help they received from a variety of sources, the tension in the building, the challenges for the protesters (many of whom had significant disabilities), and the pressures facing Heumann and the other leaders. She describes how they adapted to the government's efforts to force them out. When phone communication was cut off, the protesters relied on the deaf participants to communicate with supporters outside using sign language. She also recounts what happened when leaders of the group went to Washington to try to negotiate a settlement. Reading Heumann's account gives the reader a good sense of both the fear and excitement that pervaded the episode and the thrill when Califano finally signed the regulations. The disabled protesters had prevailed against all odds and expectations. Readers of Heumann's account may want to view the recent documentary "Crip Camp" (reviewed on H-Disability by Neil Dhingra), which documents these events with vivid film from 1977 and the current observations of participants, including Heumann.

The third section, "Berkeley, California, 1981," covers Heumann's later career as she moved into working for the US government under Presidents Bill Clinton and Barrack Obama and with the World Bank and other organizations as an advocate for individuals with disabilities. She begins the section with a discussion of the work she did to gain support for the Americans with Disabilities Act during the 1980s that eventually led to President George H. W. Bush signing the act in 1990, giving individuals with disabilities the right to participate fully in the life of the nation. She has a full discussion of how and why she came to take a position in the Clinton administration in the Department of Education, working with special education. Similarly, she devotes considerable space to her work with the World Bank to support efforts to improve the lives of men, women, and children with disabilities worldwide. Once Obama took office she again entered government service to work in the State Department on behalf of the disabled. Along the way, she recounts meeting, falling in love with, and marrying Jorge Pineda. Throughout this section, Heumann often reflects on the differences between being a disability activist on the streets and a disability advocate within the institutions of governmental and economic power. The final chapter includes her reflections on the status of disability rights and the disabled in the age of Donald Trump.

Being Heumann gives the reader a good sense of how and why Judy Heumann became one of the most prominent disability activists of the last several decades. She reflects on how her own experiences as a woman trying to make her way in an able-bodied world led her to recognize that it was not an individual problem, but a societal and cultural problem. It was, and is, a problem that could not be solved individually, but one that required, and requires, collective action. Coming of age in a time of civil rights and antiwar activism, Heumann adapted the consciousness and tactics of those movements to challenge the ableist preconceptions and barriers that had for so long restricted the lives of individuals with disabilities. She did not act alone, of course, and she is generous in acknowledging those who worked with her and helped her along the way. Being Heumann forcefully reminds us of the distance we have come since the 1970s and the hard work needed to change both laws and attitudes restricting women and men with disabilities. But Heumann's memoir of challenges met and overcome implicitly reminds us, too, of the many challenges that remain before individuals with disabilities can live and work freely in American society and in societies around the world.

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