

Book Review

Editor's Note:

Although this book was published five years ago and has been cited in subsequent scholarship in the journal, a formal review has not previously appeared in the *Review of Disability Studies*. We are honored to present this review by Luanjiao (Aggie) Hu.

Disability Rights and Justice: An International and Collective Issue

Review of *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*

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Abstract

This book review discusses *Being Heumann*, Judy Heumann's memoir highlighting her lifelong advocacy for disability rights. It details her personal struggles and successes, reflecting broader societal issues of ableism. The reviewer emphasizes the memoir's significance for understanding disability activism, noting its global relevance and inspirational value for international disability advocates.

Keywords: Judy Heumann, disability rights, disability activist

For anyone interested in knowing more about disability rights movement in the United States or about the triumphs and struggles of a disabled woman leader, the 2020 book *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist* by the late Judith (Judy) Heumann and Kristen Joiner is a must-read.

Divided into three parts based on Heumann's life trajectory, the book offers a panoramic view of Heumann's life as a disabled white woman, a polio survivor, a wheelchair user, and a lifelong disability rights activist. From reading major life events and personal reflections of Heumann, one can get an intimate insider perspective of what it is like to live with a disability in the United States since the 1950s, the struggles and vulnerabilities a disabled woman feel in the face of prevailing ableism, and what the journey looks like to be one of the pioneers in the disability rights movement. Spanning seven decades in Heumann's timeline and covering different milestones in major disability legislation in the United States, the book also provides readers a closer look at how the disability advocacy landscape came to its present form in this country.

Judy Heumann was perhaps the most renowned disability activist domestically and internationally until her death on March 4, 2023. The book can be an introductory but compelling read for anyone who wants to increase their understanding of the disability experience and disability resistance in a dominantly non-disabled world. For individuals with disabilities, Heumann's book will be highly relatable and powerful, as Heumann shared her educational experiences in both segregated and mainstream school settings, the exclusive and discriminatory treatment she had received as a disabled girl and woman navigating different spaces, the advocacy endeavors engaged by her family, herself, and later the greater disability community, and her empowering journey in disability activism and community organization. For any international readers, Heumann's life story as an American disabled female activist

can offer great insights and thought-provoking materials for comparative reflections on disability oppression and empowerment in transnational contexts. As a woman with a physical disability originally from China, I found this 175-page book highly accessible and relatable. As an international disability activist and scholar, I found Heumann's story and many of her reflections resonated with me. I am equally grateful that Heumann developed a strong voice and acquired opportunities to document her journey on multiple platforms.

Before her passing, Heumann announced on her Twitter account that her book had been translated into Japanese.

Heumann's struggles as a disabled woman are not unique to herself. Numerous disabled people around the world today still find themselves encountering similar hurdles that Heumann detailed in her book. Globally, disabled people face insurmountable obstacles to accessing education, employment, recognition, and participation in various aspects of societal life. Sadly still, as most people with disabilities in the world reside in developing countries, a significant population does not have the privilege of living in a more developed country and having access to the opportunities or resources that Heumann had, including a crucial access to education.

Heumann wrote in her book that children with disabilities in her time (1960s) were not expected to progress up the ladders of education. She initially had a hard time gaining the education that her peers without disabilities took for granted. Luckily, before Heumann became a fierce advocate herself, her parents served as solid advocates from her immediate support system. They fought fearlessly to get her access to education and inclusion in local schools. This was utterly important. Gaining access to quality education is crucial for persons with disabilities. It is the first step to break marginalization for historically disadvantaged populations and has the great potential of catalyzing greater social inclusion. Equally

important for persons with disabilities is the presence of advocates. Given the magnitude of barriers presented in disabled persons' lives, they either grow into advocates for themselves, or have others ready to speak for their case in circumstances of exclusion.

Heumann was one of the few disabled persons who succeeded in their major advocacy fights. "With a different judge, my court case could have gone completely differently," Heumann wrote, reflecting on her fight to get a teaching license by suing the New York City Board of Education. Heumann admitted that she was fortunate to have had Constance Baker Motley, the first black female judge in U.S. history, preside over her case against the Board of Education. Successful cases such as Heumann's have not been common. It takes individual determination and resources (the power and ability to fight back), collective wisdom (allies to organize and strategize in the fight), contextual support (increased rights-based awareness in the backdrop of the civil rights movement), as well as luck (the right judge who understood profoundly what discrimination meant).

Unfortunately, we more often hear and see cases of continuing discrimination and perpetual exclusion. In China, where I come from, disabled people still struggle in fights similar to Heumann's in the 1970s. In 2021, a female wheelchair user in China was denied a teaching license simply based on her disability. This came despite ranking in the top in written and oral exams, having many years of teaching experience, and holding two master's degrees (China Labour Bulletin, 2021). Another veteran Chinese teacher was denied an official teaching license because of her use of a prosthetic eye. The veteran teacher, undefeated and determined, engaged in multiple court cases against the local bureau of education. After four years of court trials, the teacher with a prosthetic eye finally won her case and received her teaching license in 2020 (Shi, 2020). Nonetheless, no local schools were willing to hire her, largely given her confrontational history with the local educational

bureau. These discriminatory encounters have been obstructing people's access to opportunities and resources and forcing disabled people to develop strategies to fight back. The outcomes have not always been successful. At times, encounters of this sort take a further toll on the health conditions of people with disabilities.

Heumann's book is one of the volumes on disability written by people with disabilities. In recent years, disability community leaders in the United States, such as Alice Wong, Haben Girma, and Emily Ladau have published edited volumes or monographs to advocate for and/or amplify the voices of the disability community. This is a continuation of the writings by persons with disabilities since the 1980s. In the U.S., among other educational, political, economic, and legislative development, including passage of the Americans with Disabilities Act in 1990, disability studies as an academic discipline also emerged. With its growth since the 1990s, disability studies contributed to the increasing influence of disability research and documented lived experiences. Popular publications such as Heumann's book constitute an important force in the disability rights movement.

Since ableism remains deeply embedded in societies across ideologies and countries, collective action is urgently needed to dismantle it. Drawing from her experience in resisting ableism, Heumann wrote: "All I knew was that we would have no power at all if we weren't united" (Heumann & Joiner, 2020, p. 104). She further observed:

Change never happens at the pace we think it should. It happens over years of people joining together, strategizing, sharing, and pulling all the levers they possibly can.

Gradually, excruciatingly slowly, things start to happen, and then suddenly, seemingly out of the blue, something will tip. (Heumann & Joiner, 2020, p. 145).

It is an international and collective issue for us to advance disability rights and justice. I see the value of introducing Heumann's book to an international audience that is interested

in advancing disability causes elsewhere. Heumann's activism and determination in promoting disability justice have the potential to inspire hope, strategies, materials, and comparative reflections for activists and organizers beyond the U.S. border.

References

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