

BOOK REVIEW

Disability Worlds

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Book Title: Disability Worlds

Authors: Faye Ginsburg, Rayna Rapp^a

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Disability Worlds invites readers to reimagine disability through an anthropological lens by delving into the social constructs that shape the experiences of those with disabilities. Faye Ginsburg and Rayna Rapp, both scholars and parents of children with disabilities, offer a deeply personal and professional perspective on how disability is navigated in society. Both authors have several publications as anthropologists and researchers of disability studies, making them well-poised experts on this topic.¹

Ginsburg and Rapp chronicle three decades of evolving disability experiences in New York City, focusing on social constructs rather than medical aspects. Unlike much of the literature that addresses specific disabilities, they examine a wide range of disabilities and emphasize societal perceptions of normalcy. The authors explore how families must reimagine kinship, caregiving, and normalcy when disability is part of their lives, noting, “Like many parents we interviewed, we learned that the unfolding of a culturally normative life course can no longer be assumed when disability is part of the household” (p. 21).

The book traces the historical treatment of disabled individuals, from institutionalization to the push for inclusion, and addresses key issues across the lifespan. Starting with reproductive technology and the ethical dilemmas it presents, the authors raise questions about the adequacy of genetic counseling for prospective parents. They also discuss the “disability cliff” and the planning required for caregiver death. The recognition of disability, while crucial for obtaining services, can impact individual identity and self-worth, a double-edged sword the authors examine in the context of educational plans and service access.

Ginsburg and Rapp acknowledge the privilege of living in a resource-rich city and being health literate, which provides access to services others might not have. They highlight the compounded challenges faced by those in rural or underserved areas, as well as the impact of social determinants of health on disabled individuals and their families.

While the authors discuss needed improvements in education, society, and politics to empower disabled individuals and their caretakers, they also celebrate areas where disability worlds have thrived, particularly in the arts. The flourishing of disability arts serves as an inspiration and a call to action for similar advances in other areas, such as health care. Notably, one-third of disabled individuals lack regular health care clinicians, raising questions about the progress of health care accessibility.

A unique aspect of *Disability Worlds* is how the authors weave together historical information, research, social constructs, and personal experiences. They provide a vivid portrayal of societal norms and systemic issues while sharing the words of those living within the system. The authors urge readers to see disability not as something to be eradicated, but as a part of the human experience that society must support and embrace under the umbrella of diversity, equity, and inclusion. They highlight how individuals with disabilities contribute positively to society, challenging the boundaries of what is considered normal. Subsequent publications would benefit from a robust discussion on the health care realm, exploring potential outside of current normalcy suggestions for improvement.

For family medicine clinicians and educators, the themes in this book are insightful and thought-provoking. The scientific drive to eradicate disability sends a message that disabled individuals represent an unwanted future. Instead, Ginsburg and Rapp envision a society that supports disabled individuals to live otherwise and thrive. Their work encourages a broader understanding of disability, not only for patients but also for learners, advocating for creative approaches to education that accommodate diverse needs and promote success.

In summary, *Disability Worlds* offers a compelling exploration of how disability shapes lives and challenges societal norms. The authors provide a nuanced perspective that blends scholarly analysis with lived experience, urging readers to rethink disability and consider how society can better support those who live with it.

***Footnote:** Rayna Rapp authored *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. She coauthored many articles with Faye Ginsburg, including “Enabling Disability: Rewriting Kinship, Reimagining Citizenship” and “Contested Lives: The Abortion Debate in an American Community.” The coauthors also have book pending publication, *Disability, Personhood, and the “New Normal” in 21st Century America*.