

## *Acknowledgments*

This book originates in our three decades of immersion in diverse disability worlds as parents, advocates, researchers, writers, teachers, and scholars. In 2018, after authoring scores of articles and giving countless presentations, we finally decided to write a book about the remarkable disability worlds we had been encountering. From the beginning, our goal has been to invite the widest possible range of readers to join us on our journeys. The ideas expressed in these pages reflect our training as anthropologists, our commitments to feminism and social justice, and our embrace of disability studies.

At Duke University Press, our redoubtable editor, Ken Wissoker, believed in this project from its earliest stages, encouraging our writing through its many ups and downs. Simply put, this book would not exist without his generous support, enthusiasm, and foresight as well as his endless patience. Thanks as well to editorial associate Kate Mullen and project manager Liz Smith, who guided us through the production of this book with extraordinary and expert care. Karen Fisher provided excellent copyediting.

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First and foremost, we are profoundly grateful to our children, Samantha and Teo, who initially introduced us to disability worlds. Their stories are woven throughout these chapters. This book reflects all that we learned

with and from them since their infancy, as new members of ongoing kinship worlds and as they grew into ever-broadening networks of friends and supporters. Finding alternative pathways through schooling for and with them was always illuminating, at times remarkable, and often frustrating. Those experiences became our initial motivation for the research on which *Disability Worlds* is based. Later, their activism and artistic passions catalyzed our own recognition and growing awareness of the significance of disability arts, from what we call third spaces to extraordinary experimental work to accessible Broadway performances. Conversations and experiences with them about their futures shaped this book's last chapter.

We thank the many, many people who shared their disability experiences and stories with us, generously welcoming us into their homes, workplaces, and advocacy meetings, introducing us to family members and allies, showing us their films, and inviting us to sit in on rehearsals and book readings, as well as their life-changing performances. Some have been promised anonymity and cannot be named; we are indebted to them and to the people we are able to acknowledge here. To protect privacy, we adopt pseudonyms for most of the people with whom we had formal interviews or informal conversations. We use actual names for those who are public figures or who have already published under their own names on topics covered in this book. Our sincere apologies to anyone we inadvertently left off this always-expandable list.

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Mara Mills, a groundbreaking disability studies scholar and historian of science and technology, has been a spectacular ally and fellow traveler extraordinaire as cofounder and codirector with Faye of the NYU Center for Disability Studies. We were privileged to be coresearchers, authors, and editors with Mara, writing several grants, starting in March 2020 when the pandemic hit; we were concerned that the inequalities faced by disabled people during the public health emergency would be underrecognized. Three of our early essays on disability experiences during COVID were coauthored with Mara; some of that work is incorporated into chapters 6 and 7 (see below). Fortunately, we received three years of funding for what became the Disability Covid Chronicles research group, incorporating the three of us as well as a cohort of other interdisciplinary disability studies researchers focused on the diverse experiences of disabled people in New York City as it became the epicenter of the US pandemic. The core group included Assistant Professor Harris Kornstein, postdoctoral fellow Yan Grenier, and (at the time) doctoral students Salonee Bhaman, Shuting Li, Nadia Mbonde, Emily Rogers, and Cara Ryan. We met biweekly via Zoom over two years to share the team's research progress and exchange ideas and findings with other COVID researchers. We are grateful for all we learned in those many encounters. Our collective work appears in *How to Be Disabled in a Pandemic* (NYU Press, 2024), coedited with Mara Mills and Harris Kornstein, with additional chapters written by other New York City researchers and disabled allies and activists. Additionally, Faye coedited a special dossier of *Film Quarterly* called "New Disability Media" (winter 2022) with film scholar B. Ruby Rich and disability activist and media maven Lawrence Carter-Long; the many contributors for this shared collaboration shaped portions of chapter 6.

Other insights influencing this book emerged from a Wenner-Gren international symposium on disability worlds that we organized in 2018, which expanded our understanding of the politics of impairment and disability

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In the days before iPhone Voice Memos made this an outdated technology, several generations of students worked with a pedal transcription machine to create our archive of interviews. Thanks to NYU students Alyson P. Atwell, Amanda Onalaga, and Victoria Ann Swerski. We are especially grateful to anthropologist Amikole Maraesa, who served as our first transcriber during her graduate studies and also introduced us to her robust network of mothers of children with Individualized Education Plans in the New York City public schools. Our former doctoral student, anthropologist Cara Ryan, who studies autism in France, was stellar, preparing the manuscript bibliography and index, reading early versions of chapters, and introducing us to invaluable emerging literature in critical autism studies.

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Portions of research and writing that went into this book have appeared in earlier publications.

#### DISABILITY WORLDS

We first used the phrase *Disability Worlds* as a title for a review essay in 2013, again in 2020 for a journal special issue on anthropology and disability, and finally for the title of this book.

Ginsburg, Faye, and Rayna Rapp. 2013. "Disability Worlds." *Annual Review of Anthropology* 42:53–68.

Ginsburg, Faye, and Rayna Rapp. 2020. "Disability Worlds." *Current Anthropology* 61 (suppl. 21).

Parts of various chapters appeared in the following earlier articles and books.

#### INTRODUCTION

Ginsburg, Faye, and Rayna Rapp. 1999. "Fetal Reflections: Confessions of Two Anthropologists as Mutual Informants." In *Fetal Subjects, Feminist Positions*, edited by Lynn M. Morgan and Meredith Wilson Michaels, 279–95. Philadelphia: University of Pennsylvania Press.

#### CHAPTER 1

Ginsburg, Faye, and Rayna Rapp. 2024. "Crippling Reproduction: Intersections of Pregnancy and Disability." In *A Companion to the Anthropology of Reproductive Medicine and Technology*, edited by Cecilia Van Hollen and Nayantara Appleton. Hoboken, NJ: Wiley.

Rapp, Rayna. 1999. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, chapters 5 and 9. New York: Routledge.

Rapp, Rayna. 2010. "Chasing Science: Children's Brains, Scientific Inquiries, and Family Labors." *Science, Technology and Human Values* 36 (5): 662–84.

Rapp, Rayna. 2011. "A Child Surrounds This Brain: The Future of Neurological Difference According to Scientists, Parents, and Diagnosed Young Adults." In *Sociological Reflections on the Neurosciences*, edited by Martyn Pickersgill and Ira Vankeulen, 3–26. London: Emerald.

Rapp, Rayna. 2015. "Big Data, Small Kids: The Globalization of Neuroscience." *BioSocieties* 11 (3): 296–316.

## CHAPTER 2

Rapp, Rayna, and Faye Ginsburg. 2001. "Enabling Disability: Rewriting Kinship, Reimagining Citizenship." *Public Culture* 13 (3): 533–56.

Rapp, Rayna, and Faye Ginsburg. 2011. "Reverberations: Disability and the New Kinship Imaginary." *Anthropological Quarterly* 84 (2): 379–410.

## CHAPTER 3

Ginsburg, Faye, and Rayna Rapp. 2010. "The Social Distribution of Moxie: Following the Legacy of Christine Sleeter." *Disability Studies Quarterly* 30: 1–12.

Rapp, Rayna, and Faye Ginsburg. 2011. "The Paradox of Recognition: Success or Stigma for Children with Learning Disabilities." In *Contesting Recognition: Culture, Identity and Citizenship*, edited by Janice McLaughlin, Peter Phillimore, and Diane Richardson, 166–86. London: Palgrave Macmillan.

## CHAPTER 4

Ginsburg, Faye, and Rayna Rapp. 2013. "Entangled Ethnography: Imagining a Future for Young Adults with Learning Disabilities." *Social Science and Medicine* 99:187–93.

## CHAPTER 5

Ginsburg, Faye, Mara Mills, and Rayna Rapp. 2020. "Lessons from the Disability Front: Remote Access, Conviviality, Justice." *ConTactos*, May 2020. <https://contactos.tome.press/lessons-from-the-disability-front/>.

Ginsburg, Faye, Mara Mills, and Rayna Rapp. 2022. "The Swell: Disability Arts in the Time of Covid-19." In *Curating Access: Disability Art Activism and Creative Accommodation*, edited by Amanda Cachia, 17–30. New York: Routledge.

Ginsburg, Faye, and Rayna Rapp. 2015. "No Judgments: Fieldwork on the Spectrum." *Somatosphere*, July 20. <http://somatosphere.net/2015/07/no-judgments-fieldwork-on-the-spectrum.html>.

## CHAPTER 6

Ginsburg, Faye, and Rayna Rapp. 2015. "Making Disability Count: Demography, Futurity, and the Making of Disability Publics." *Somatosphere*, May 11. <http://somatosphere.net/2015/making-disability-count-demography-futurity-and-the-making-of-disability-publics.html/>.

Ginsburg, Faye, and Rayna Rapp. 2016. "#cripthevote: What's the Crisis of Liberalism Got to Do with It?" Hot Spots, *Fieldsights*, October 27. <https://culanth.org/fieldsights/cripthevote-whats-the-crisis-of-liberalism-got-to-do-with-it>.

Ginsburg, Faye, and Rayna Rapp. 2017. "Making Accessible Futures: From the Capitol Crawl to #cripthevote." *Cardozo Law Review* 39 (2): 101–20.

Ginsburg, Faye, and Rayna Rapp. 2017. "Crippling the New Normal: Making Disability Count." *ALTER: European Journal of Disability Research* 11 (2): 179–92.

Ginsburg, Faye, and Rayna Rapp. 2017. "Crippling the Future: Making Disability Count." In *Anthropologies and Futures: Techniques for Researching Emerging Worlds*, edited by Andrew Irving, Sarah Pink, Juan Salazar, and Johannes Sjöberg, 43–60. London: Bloomsbury.