DISABILITY WORLDS

FAYE GINSBURG & RAYNA RAPP

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Photo by Michelle Schwab, directed by Samantha Myers. Mural by
Jeff Rose King and Carlos Arevalo. Courtesy of the artists.

To our children, Samantha and Teo, and all the others
who opened doors to their disability worlds

Contents

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 both in and beyond North America. We thank Danilyn Rutherford, president of the Wenner-Gren Foundation, for her support and program associate Laurie Obbink for organizing and enabling this gathering. We acknowledge with appreciation the work of the participants: Renu Adhlaka, Pam Block, Tom Boellstorff, Patrick Devlieger, Arseli Dokumaci, Michele Friedner, Richard Grinker, Cassandra Hartblay, Devva Kasnitz, Beatriz Miranda, Herbert Muyinda, Laurence Ralph, Ayo Wahlberg, Susan Reynolds Whyte, and Tyler Zoanni. The four days we spent together at the Hacienda del Sol in Tucson, Arizona, nurtured global networks among anthropologists working on disability, resulting in a special issue of *Current Anthropology* (see below).

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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* * *

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* * *

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

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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.

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

INTRODUCTION

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Introduction

Encountering Disability Worlds

Birth of a Research Project

This book emerges from a long, intertwined journey into what we call American disability worlds, a territory we encountered when our children both received diagnoses of learning disability (LD). As nondisabled mothers and anthropologists, we first acquired practical knowledge of the LD world as parents. Over time, we learned that our children's labels were more than individual; they were also shaped by medicalized stigma, harsh social policy, public neglect, ableist exclusions, and increasingly by activism and lively cultural innovation.

The project that would eventually become this book has a backstory, initially based on our shared anthropological interests in women's experiences of reproduction, from the abortion controversy (Ginsburg 1989, 1998) to the rise of late twentieth-century reproductive technologies (Rapp 1999, 2001), sites of constant negotiation in American cultural life. In 1988, a pregnant Faye volunteered to serve as a research subject for Rayna, then studying women's experiences and decision making around amniocentesis. It is an enduring irony of our collaboration that when Rayna asked Faye what she felt about being the subject of such prenatal testing (at that time limited to a small number of conditions), she replied, "Well, now I know my fetus doesn't have these few things wrong with it. And for the rest, we'll see." When her daughter Samantha was born a few months later, she had a set of mysterious and life-threatening symptoms that landed Faye, Sam, and Fred (Faye's husband and Sam's father) in the hospital for months pursuing what medical anthropologists call "the diagnostic odyssey" (cf. Frank 1997). At six months, Sam was finally diagnosed with a very rare autosomal recessive Ashkenazi Jewish genetic disorder of the autonomic nervous system, familial dysautonomia (FD).[1] While Sam's predicted life expectancy at birth was only ten years, when she in fact reached that age in 1999, she appeared on national television on the children's show *Nick News*, sharing her stories of life with FD, becoming a young spokesperson for disability inclusion and an educator about her rare disease (Myers 2000). In 2022, against the odds, she had her thirty-third birthday.

The fact that Sam's rare genetic disorder could not then be detected with prenatal testing intensified our interest in the intersection of disability and reproductive technology (Lerner 2009; Lindee 2005). Our 1999 essay "Fetal Reflections: Confessions of Two Feminist Anthropologists as Mutual Informants" highlighted our growing concern about the implications of a diagnosis via prenatal testing (Ginsburg and Rapp 1999). How could potential parents possibly make an informed decision about whether or not to continue a pregnancy after receiving a "positive diagnosis" in the absence of any reality-based understanding of what it means to live with a prospective family member with a specific impairment? Why, we wondered, was there so little dialogue between two distinctive "social funds of knowledge": genetic diagnosis and "disability expertise" (Hartblay 2020a)?

In confronting this concern, we took guidance from the groundbreaking work of the late disability scholar and activist Marsha Saxton. By the 1980s, she had already been interrogating the boundaries that kept these social funds of knowledge segregated, offering significant disability rights critiques of prenatal genetic testing. For example, Saxton underscored that

> it is ironic that just when disabled citizens have achieved so much, the new reproductive and genetic technologies are promising to eliminate births of their kind—people with Down Syndrome, spina bifida, muscular dystrophy, sickle cell anemia and hundreds of other conditions. The American public has apparently accepted these screening technologies based on the "common sense" assumptions that prenatal screening and selective abortion can potentially reduce the incidence of disease and disability and thus improve the quality of life. A deeper look into the

> medical system's views of disability and the broader social factors contributing to disability discrimination challenges these unexamined assumptions. (1998, 1–2)

Despite the significance of such insights, disability awareness and the practice of genetic testing—both escalating dramatically over the last few decades—were rarely brought into the same conversation. Following the lead of Saxton, we started "cripping reproduction," using "crip" as both a noun and a verb in keeping with its reclamation as a cultural sign by disability studies scholars as well as the disability rights and justice movement (Lewis 2015; McRuer 2006; Sandahl 2003), although there are robust critiques of the term (Kulick and Rydström 2015, 13–17).[2] As disability scholar Sami Schalk explains:

> Crip is a term many people within disability studies and activist communities use not only in reference to people with disabilities, but also to the intellectual and art culture arising from such communities. Crip is shorthand for the word "cripple" which has been (and is) used as an insult toward people with disabilities, but which has been reappropriated as an intra-group term of empowerment and solidarity. Thus, crip "is a term which has much currency in disability activism and culture but still might seem harsh to those outside those communities." (Schalk 2013, citing Kafer 2013, 15)

This shift in language signaled the application of a disability advocacy lens to our writing on reproduction, calling for a more critical dialogue between the practice of genetic testing and broader efforts at disability inclusion. Increasingly, we found ourselves exploring two powerful but contradictory aspects of contemporary life. Biomedical technology, particularly assisted reproductive technologies, continues to hold out the deeply American and neo-eugenic promise of perfectibility, given that pregnancies bearing fetal anomalies detected through prenatal testing are frequently terminated. Such interventions raise expectations of individual control over the value of impaired "bodyminds," a term we borrow from disability scholar Margaret Price. She insists that "mental and physical processes not only affect each other but also give rise to each other. . . . They tend to act as one, even though they are conventionally understood as two—it makes more sense to refer to them together, in a single term" (Price 2015, 269). Too often, prenatal screening takes place without considering not only the interdependence of bodyminds, but also the crucial role of kinship, community, and religion that may or may not offer resources for support and inclusion (or exclusion) of people with disabilities. By contrast, the disability rights movement in the twentieth century was followed by the disability justice movement in the twenty-first, which underscored how ableism relates to other kinds of oppression based on race, class, gender, and sexuality. Together they have created a robust ethical and political framework for democratic inclusion across the full range of human variability. Both are part of the biopolitics of disability in contemporary American life. Disability is imbricated in the telos of the techno-scientific imaginary of bodily perfectibility, as well as in the utopian possibilities invoked by social movements for democratic inclusion of those too long excluded. We have called this paradoxical tension the "doubled telos of modernity," a phrase we invented to describe this apparent contradiction (Rapp and Ginsburg 2001). How are these different and seemingly conflicting imperatives reshaping life in the twenty-first century? Through our research, we have come to understand that there is no absolute line separating these two orientations. These emergent formations, both public and intimate, require political will as well as a recognition that disability worlds are projects of cultural creativity and reinvention, acts of world building that routinely intersect other biopolitical regimes.

Our conversations deepened when Rayna's second child, Teo, born three years after Sam, was diagnosed with significant learning disabilities in the early primary grades. Eventually, our children went to the same "special ed" primary and middle schools.[3] We kept the conversation going as we navigated the labyrinth of educational bureaucracies in procuring the services to which they were entitled. Rayna's son had a garden-variety diagnosis of dyslexia that nonetheless required hours of daily scaffolding to get him through schooling, not to mention lawsuits against the City of New York to secure funding for appropriate accommodations. Faye found that Samantha's FD affected her learning style along with a panoply of other more severe complications that required feeding tubes, hourly eye drops, pharmaceutical supports, and bodily techniques for managing her dramatic swings in blood pressure. By necessity, we followed the path of so many parents of kids diagnosed with various LDs as we sought support for our children and their alternative ways of learning about and engaging with the world. Like most parents discovering that their kids need "special education" services, we were initially absorbed in this new reality for which we were unprepared at both pragmatic and existential levels. Over time, we recognized that our learning curve was much steeper than that of disabled parents, who are probably more expert at mobilizing support for their children and challenging discrimination that undermines their value as parents, an issue we did not have to face. As Ella Callow, Indigenous lawyer, director of disability access at the University of California at Berkeley, and coauthor of *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, tweeted, “The entire, explicit purpose of Eugenics was to prevent Disabled people from having kids & creating more ‘unfit’ people. . . . Ignoring the needs of disabled parents & their kids reflects internalized eugenicism” (April 18, 2022).

In an effort to carve viable pathways for our children through the overwhelming bureaucracy, we dedicated ourselves to learning about their particular issues while locating educational settings and services that would meet their needs. As close friends and longtime research partners, we were engrossed in constant dialogue as we tried to make sense of our status as nondisabled newcomers to what we started to call the disability world (Ginsburg and Rapp 2013). The idea of disability worlds offers a framework embracing the challenges and world making that disability brings to social life.[4] This is despite enduring ableism that pathologizes people with disabilities as marginalized or “suffering subjects.” Instead, we stress how experiences of disability may incite everyday creativity and provoke new ways of understanding human difference in specific locations. Dealing with all the issues we confronted, along with our kids—complex medical problems for Sam and stigma faced by both—turned us into fierce advocates for our children and accidental activists in our communities, fighting for educational opportunities, while the daily lives of our families were increasingly braided together (Panitch 2007).

Clearly, we were not alone: in New York City, a substantial 19.5 percent of students are recommended for an Individualized Education Plan (IEP) (National Center for Education Statistics 2019). This document—sometimes called a passport to “special education”—mandates the services a school must provide in a timely manner for any diagnosed pupil (Veiga 2022). Nationally, the number hovers around 15 percent (National Center for Education Statistics 2022). The gap between New York City and the national numbers is not accidental; the city is home to immigrants from all over the world, many of them English language learners whose children also often get classified as “special education” students. Furthermore, medical diagnoses and care are more readily available in the city than in rural locales, adding to the number of pupils labeled for services. Additionally, the city’s many economically and educationally disadvantaged children are often disproportionately classified for “special education,” whether appropriately or not, increasing those figures.

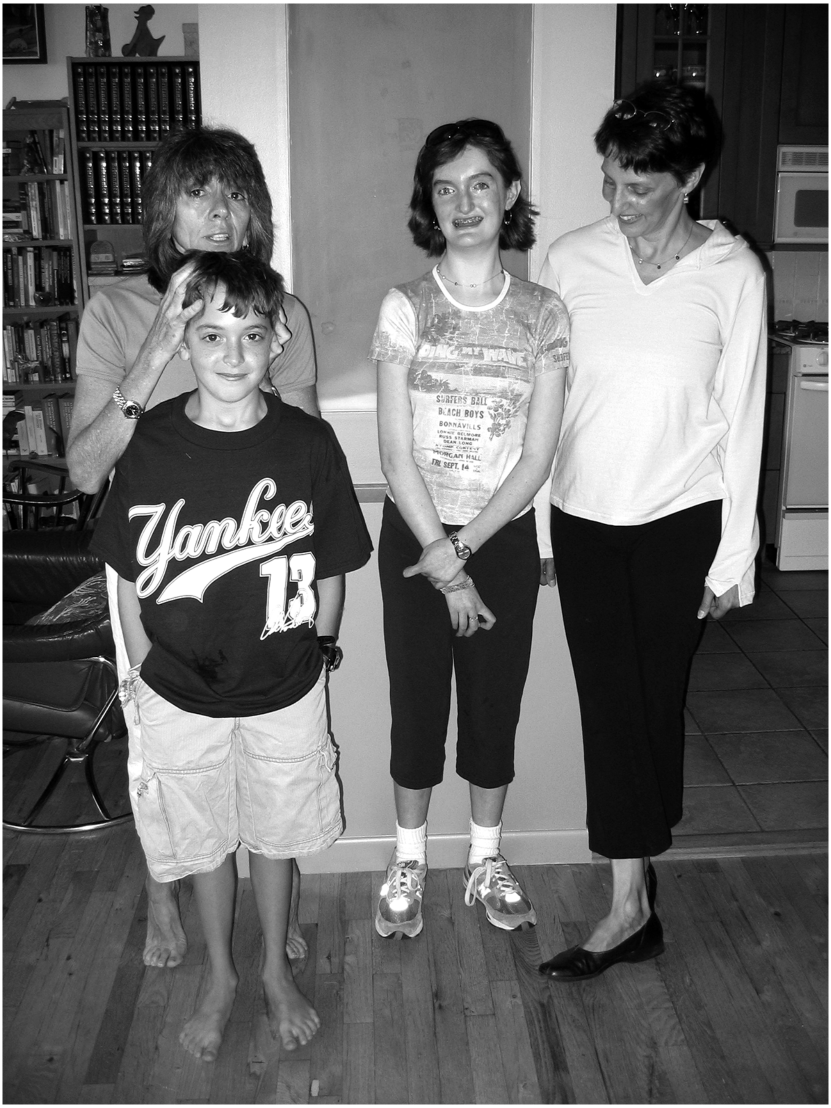

FIGURE I.1. Rayna, Samantha, Faye, and Teo at Rayna's apartment, spring 2003. Photo courtesy Mira Rapp-Hooper.

The confluence of these factors makes the metropolitan area's higher proportion of children in this category unsurprising.

These metrics reflect a rapidly expanding demographic that undergirds a profoundly different disability world in the twenty-first century than the one we encountered growing up in the 1950s and 1960s when institutionalization was still in place. When our kids were diagnosed, we asked ourselves, where were all the children like our "atypical kids" when we were their age, prior to national legislation that opened classrooms to disabled children? We had no recollection of similarly labeled pupils in our public school classrooms in the mixed middle- and working-class neighborhoods on Long Island and in South Chicago where we came of age. When we queried our parents about this situation, long-submerged stories quickly surfaced, revealing what "normalcy" and its unrecognized violence meant in the mid-twentieth century, and on into the 1970s. Clearly, we realized, a code of silence produced by discriminatory etiquette and shame had blanketed our neighborhoods where everyone knew but did not discuss the differences hidden in untold family histories, including the secrecy surrounding institutionalization. Our parents recounted tales of neighbors whose children with Down syndrome, cerebral palsy, and other disabilities were barred from attending school, sequestered at home, or sent to institutions (Senior 2023). The only vivid exception we both recalled were classmates who had survived polio and were back in our schools with braces and crutches, sometimes consigned to basement classrooms with other "special ed" kids. And of course, sadly, some died young in an era when life-saving medical measures that we now take for granted were not yet available. The 2020 memoirs of two prominent disability activists, Riva Lehrer and the late Judith Heumann, offer compelling chronicles of the discrimination they faced as children seeking an education in a pre–Individuals with Disabilities Education Act era (Heumann and Joiner 2020; Lehrer 2020).[5] This form of unspoken segregation characterized how different bodyminds were barred from public inclusion at a time when some states still criminalized even the public presence of people with disabilities under harsh legislation commonly known as "the ugly laws" (Schweik 2009).

By the 1960s, parents of these children, primarily mothers, had not only fought for their kids' rights but also sought professional training, sometimes after helping their struggling children learn to read. They became a hidden cadre of gendered paraprofessional support for their own and other atypical learners. It took us some time to appreciate that the presence in our public schools of these underrecognized-but-essential support staff—including our own mothers, who both worked as remedial reading teachers—was part of a historical trajectory. Indeed, their employment was linked to the rise of "special education" mobilized by parent and community activism. This movement led to important national educational policy changes led by families with labeled children who were struggling to find creative alternatives to typical family life in the face of routine discriminatory expectations and practices.

We also learned how American public schools were transformed by the passage of the federal Rehabilitation Act of 1973, in particular Section 504, and in 1975, the Education for All Handicapped Children Act (renamed the Individuals with Disabilities Education Act or IDEA in 1990). For the first time in American history, these groundbreaking laws mandated that students with disabilities would have the legal entitlement to "free and appropriate public education in the least restrictive environment." At long last, this new legislation extended educational rights to all American children, creating space for disability worlds to eventually emerge, within and beyond school settings. Yet whatever utopian imaginary legal mandates might offer, the battles to achieve educational equity, played out on the intersecting grounds of race, gender, class, ethnicity, and disability, are ongoing. Changes in the law, we discovered, are only one part of this complex story. The shadow of powerful structural changes in policy, medicine, the economy, and culture also loom over and shape our research.

Beginning in the early 1970s, deinstitutionalization brought people who had been segregated by social convention, medical diagnosis, and sometimes law back to their families and communities when possible, a process that continues to this day. Moreover, "special education" services, especially for people with learning disabilities, have expanded dramatically over the last few decades. Federal legislation requires medical diagnoses in order to access resources, resulting in one of the central concepts that we developed in our analysis: the paradox of recognition. This phrase calls attention to the Foucauldian dilemma that bureaucratization creates for students with impairments who cannot access important services without a diagnostic label; yet paradoxically the label itself both creates a surveilled population and has its own stigmatizing consequences. In other words, the category *learning disabilities* as a social fact has become increasingly medicalized and sometimes contested, processes that open certain doors while potentially closing others. The increasing recognition of LD as a classification is part of an expansion and ongoing transformation of disability categories more generally.

Demographic projections from the US Census and accompanying studies have long underscored that the percentage of Americans with disabilities—a growing absolute number—is also a steadily expanding portion of the population. Over the decades, the number of people considered disabled has continued to steadily climb; it is now over 25 percent of the population.[6] This is a tectonic shift with enormous implications for how civic culture accommodates or excludes embodied and cognitive differences across the life span. These census numbers need to be disaggregated to understand how the category of disability is actually growing. School-age children with LDs have doubled in each decade since the 1970s, now fueled by the increase in autism diagnoses (Brault 2012). Medical advances have saved and often improved the quality of life for those diagnosed with serious conditions and/or chronic illness, who are now living longer lives (Anderson and Horvath 2004). Many are surviving with disabilities who might not have in the past. They are living independently, sometimes with assistants, with families or friends, or in supported environments integrated into community life, or too often in less than desirable settings with inadequate support.

These growing numbers make clear that the shape of disability integration will continue to be central to fraught public and private conversations around inclusion, access, caregiving and their costs. As parents, we experienced this close to home. Our practical and existential knowledge expanded as we learned to provide for our children what disability activist Mia Mingus (2011) calls "access intimacy," "that elusive, hard to describe feeling when someone else 'gets' your access needs." Faye, for example, would often refer to herself as "Sam's external autonomic nervous system" as she learned to anticipate and help her manage the wild swings of blood pressure and unpredictable autonomic crises that FD entails. Rayna came to think of herself as Teo's reading machine as she took part in their nightly homework regime, passing books back and forth for a choral performance of whatever assignment he was addressing. Like many, we came to understand the significance of such care work and interdependence as simultaneously personal and political.

Immersing ourselves in the realities of living with disability, our collaboration deepened as we became ethnographers of our own and one another's journeys. Our access intimacy extended to accommodating one another's experiences supporting our disabled kids. Many writing sessions were held in the family waiting room of the ICU, Samantha and Faye's second home for years. Our conversations whiplashed between looking up alternative treatments and finding distracting videos for Sam along with brainstorming our next article or presentation. In such liminal spaces, we were often sitting next to other families who were ordering Chinese takeout or receiving end-of-life counseling from a chaplain of their religious tradition. Meanwhile, Rayna was sending Faye communiqués from the front lines of what Teo called "The Board of

Dread" as she took on her warrior mom persona to get him learning support and respect. The concept of interdependence, foundational to feminism and disability studies, was our praxis. We came to understand and value that we were constantly operating on crip time, the extra time required for accommodations that disabled people and their supporters might need to perform tasks in a world with many barriers. As one of our research participants recently posted on Facebook:

> The last 24 hours: taxes, special needs trust, and now arm wrestling with access-a-ride [AAR] over why my [disabled] husband can't go for recertification in Staten Island . . . Why does this need to be explained? (. . . AAR sends a car to take him there and return him—right?—and pandemic driver no-shows isn't an issue?) The rant is over. Going to pick my [disabled] kid up from school where his shining ray of light face will make up for all this garbage. Followed by my husband's ray of light face. But really some days the bureaucracy around care is truly overwhelming. (April 15, 2022)

In short, our pacing, like that of many we encountered in our research, responded to the interruptions, delays, and rearrangements that interdependency demands.

Going Empirical

In 2006, we decided we were ready to go empirical. Although by then we had been writing together on disability, reproduction, and other topics for over a decade, our first joint fieldwork project with external funding began the following year. Our formal inquiry started with two foundational questions that mirrored our own experiences: Practically, how do diverse families with a recently labeled child manage the logistics required to meet their youngster's school needs and social integration? Existentially, how do they reimagine family life with this difference? New York City, our location, offered an abundance of families facing these issues. Moreover, the metropolitan area is famous for its broad spectrum of race, class, immigration experience, gender/sexuality, and religious diversity. Additionally, the Big Apple is well known for failed public support for disabled students in and out of school, as well as lively cultural innovation for people with disabilities in alternative education, the arts, and access to cultural venues. In short, the city offers the range of problems and possibilities that characterize the complexity of the contemporary experience of disability in the twenty-first century.

Based on many encounters and conversations in waiting rooms, on school playgrounds, and at Department of Education meetings, to name a few sites, we developed a sample of over fifty disabled families coming from a range of socioeconomic, cultural/ethno-racial, and religious backgrounds across New York City's five boroughs. All had children with learning differences requiring an IEP, the federally mandated personalized roadmap outlining accommodations for each pupil diagnosed with a disability.

In our qualitative semistructured interviews, we discovered how our interlocutors—people with whom we spoke for this research—were struggling with as well as reimagining their family stories in resistance to hegemonic norms. Throughout this book, we name people whose words we quote from public sources and/or who have given us permission to identify them. The rest of our respondents are identified by pseudonyms to protect their confidentiality, as promised. All quotations from formal interviews with interlocutors or field notes are identified by the year in which they occurred. Occasional phrases drawn from ongoing informal conversations are not dated or attributed to a particular speaker.

Further, we learned that neither the children so labeled nor the label itself are easily domesticated or reified. The term *learning disabilities*, for example, was an often-fuzzy classification of disabling difference with its own genealogy as it displaced profoundly stigmatizing earlier terms such as "mild mental retardation," "minimum brain damage," and "Mongolism" (Sleeter 1987). Indeed, the shifting, unstable nature of the category itself became part of our analysis and writing, as we came to understand our research in broader social and historical contexts (Ginsburg and Rapp 2010). We have kept up with many families, reinterviewing over twenty-five of them as they passed through the life course, the educational system, and beyond, balancing complex social situations and sometimes medical diagnoses, embracing disability identities and creating new understandings of bonds of kinship: chosen, biological, and otherwise. Their children, many of whom are now adults, are also increasingly part of our conversations as they have developed new understandings of what it means to live with disabilities and imagine "accessible futures" (Kafer 2013).

With the arrival of COVID-19 in 2020, we returned to some of these families once again to learn how they were managing during the intense challenges to disabled people posed by the pandemic. What we learned appears as part of our conclusion to this book. One of our earliest findings was that our interlocutors—and especially mothers—spent years creating alternative kinship stories that reclaimed their children from stigmatizing narratives of family life and medical diagnostic labels, as disability became a regular feature of their domestic life (see also Bérubé 1996; Grinker 2021; Kittay 2019; Landsman 2009). We began writing about this transformation as "new kinship imaginaries," describing the experiences of our own and other "disabled families" (Rapp and Ginsburg 2001, 2011b). We see new kinship imaginaries as alternative formations built by families as they reframe "culturally shared and socially transmitted representational assemblages that interact with the personal imagination and are used as meaning-making devices, mediating how people act, cognize and value the world" (Salazar 2020, 770). In other words, parents, siblings, grandparents, and intimate allies accept the challenge of incorporating an atypical child into their rhythms and routines in ways that transform normative familial life. This paradigm shift for ourselves and our respondents often occurred as people realized their realities didn't map easily onto preexisting models of American family life. We were not alone in starting our journey by tossing out typical child development books in favor of our hard-won knowledge of alternative routes based on access intimacy with our children's unique developmental paths. With few available models for "life with a difference," we were among many who were producing what we think of as familial crip counternarratives. These are stories with the radical potential to retrieve people with disabilities from the clinical framework of diagnosis and pathology, alternatives to a fantasy image of perfect bodily health, beauty, and functioning, what disability scholar Rosemarie Garland-Thomson (1997) calls normate expectations.

Such narratives have often been marginalized and even silenced until the recent disability memoir boom in the twenty-first century (Couser 2009, 2016; Robertson 2015). Collectively, such stories, whether formally published or informally circulated, reframe the implicit norms and expectations of the life course as the experience of disability reverberates beyond the household, challenging taken-for-granted assumptions in unanticipated ways. Often, these paralleled our own lives, conceived against the grain of conventional ideas of what constitutes appropriate parenting, a child's success, and expected cycles of family life as we drew our own distinctive roadmaps. As our ethnographic research developed, we quickly recognized the significant gap between the legislative promise of equity and inclusion for those with disabilities and the problematic realities most faced: overwhelming bureaucracies, aging infrastructures, and ableist attitudes have generated enormous frustration. Such circumstances have motivated many to not only create new narratives but also, at times, to undertake unanticipated action. Sometimes this gap became the space of potential cultural transformation that interested us as both anthropologists and advocates. The prominence of activism on the part of many of our subjects across a broad range of backgrounds was particularly striking as they met the challenge of creating a more hospitable world for their children and, by extension, all people with disabilities and their allies. They learned and embraced their children's rights and the need to stand up for them. Many developed new forms of courage and creativity, what we came to think of as "the social production of moxie" (Ginsburg and Rapp 2010), repurposing the noun *moxie*, a once-popular American colloquialism indicating the ability to face life's obstacles with spirit and ingenuity. In the words of Dan Habib, a filmmaker and parent advocate: "The birth of our son Samuel brought the disability rights movement into our living room" (Habib 2007). The Habibs, like other families, became involved in activism, in their case through their films and accompanying media campaigns, most recently with Dan and Sam's codirected film *My Disability Roadmap* (Habib and Habib 2022).

Lest this sound too celebratory, we also witnessed ongoing resistance, both passive and active, to this kind of change. Some negative encounters were infrastructural and part of daily life in the city: the all-too-frequent lack of compliance with curb cuts on New York City streets and chronically broken elevators in subways and other locations such as the Department of Education, along with the frustrations of a constantly hapless transportation service, Access-A-Ride (or as Samantha called it, "Access-A-Ride-Not") (Wilson 2020). Others were bureaucratic and interpersonal, the kind of experiences we shared with many of our interlocutors. For example, families spoke indignantly of their run-ins with hostile educators who had mastered the fine art of counseling out children with learning disabilities from their public, private, and religious schools without directly saying they were not welcome. Clearly, the passage of legislation such as the IDEA and the 1990 Americans with Disabilities Act (ADA) were the necessary but not sufficient steps to creating a welcoming disability world. Some thoughtful educators attempted to address this need with innovative programs that also had market potential. For example, we participated in the inaugural New York City session of Schools Attuned, a training program for public school teachers to sensitize them to working with the strengths of "special education" students rather than just remediation of diagnosed problems, that is, to focus on capacity rather than incapacity.

For those who have had the support of "special education," however imperfect, the landscape only gets bleaker as students age out of high school. There is no clear vision of what to anticipate when living independently itself is in question, as well as the support systems needed to make it possible. Finishing school is itself an issue. In NYC, dismal high school graduation rates for disabled students remain stubbornly low. Many students in the New York City metropolitan area with LD are exiting high school without the skills and support required for the adult life they desire, undermining inclusion's promise as a route to expanded social opportunity and implicating the need for ongoing family and community support (ARISE Coalition 2011).

Despite federal mandates for post–high school transition planning, such services remain spotty, a profound dilemma that is barely recognized in public discourse on disability. As we learned from an important report by Advocates for Children, many young adults in "special education" in NYC are "Transitioning to Nowhere" (Silverman 2007), a chilling but apt title. We were struck by the spatial metaphor of *nowhere* used in that report, echoing the sentiments of so many of our respondents whose language about the lack of future possibilities frequently suggested danger and hopelessness. In the words of one of our interviewees, a mother of a young adult on the autism spectrum, "It's an unlatched window out there." She was describing the affective sense of what many fellow travelers call "the disability cliff" (Bagenstos 2015).

As we began to see the fragile and fraught nature of transition for so many young adults with cognitive and developmental disabilities and their families, we expanded our research to incorporate a new collaboration, this time with visionary educators. We encountered and explored alternative high school transition and college programs, and helped establish a model transition program in collaboration with NYU colleagues and two local independent high schools for students with learning disabilities. Initially called SKILLS, an acronym for Skills and Knowledge for Independent Living and Learning, the program we helped launch was incubated for two years in temporarily unused space in our Anthropology Department, a kind of experimental lab school that we were able to observe as it emerged.

Over time, our study, which initially focused on families, schools, the world of "special education," and transition, became more capacious. We expanded our research to include the disability expertise of a wide range of respondents as we grappled with the complex questions raised by LD across the life course, including those we encountered as our own children were becoming young adults. We discovered remarkably diverse forms of cultural innovation. In our fieldwork, we encountered many lively projects that invited cautious optimism, despite the sometimes-glacial pace of progress toward fulfilling the promise of a society inclusive of disability. It seemed to us that America was undergoing a slow sea change in the public visibility, acceptance, and accommodation of disability as a fundamental aspect of human difference. We were struck by the originality of the many programs we were encountering, such as the Partnership for Children's Rights (now part of Mobilization for Justice), a retired lawyer's initiative to get legal, educational, and economic support for low-income learning-disabled students.[7] Indeed, after visiting many sites where we tripped over boxes being unpacked while ramps were installed and accessible workspaces were under design, we started to use the phrase "the paint is always wet" as a shorthand material description of the surprising recency of many of these projects.

We encountered new initiatives to support college education for young adults with learning differences. A handful of older private institutions such as Landmark College, founded in 1985, have offered tertiary education for a small number of LD students whose families could afford the high tuition. In 2008, the Higher Education Opportunity Act opened the doors for many more students across class and cultural backgrounds. This legislation provided the first federal funds underwriting college attendance for those with intellectual disabilities. With this support, Think College (initially a project of the Institute for Community Inclusion at the University of Massachusetts Boston) became a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disabilities.[8] The work of this initiative has helped open doors for those long classified and stigmatized as cognitively incapable of benefiting from postsecondary education. We draw on insights gained from exploring these groundbreaking transition and college programs, as well as those that emerged from ongoing conversations with a broad network of advocates in NYC working on the politics of higher education, job creation, and disability inclusion.

Beyond expanding innovation in the educational realm for people with disabilities, we encountered a wide range of creative projects by disabled artists who have been constructing new cultural imaginaries centered on disability experiences and aesthetics, work that accelerated in the twenty-first century with the rise of "the new disability arts movement" (Mills and Alexander 2022). Indeed, disability arts in the city go back at least to the 1970s, foreshadowing the remarkable florescence we had the privilege to encounter more recently (Kaggen 1997; Roberts 2015). In the case of disability arts, form, content, and community are deeply intertwined as the materialities of access are increasingly incorporated into both creative production and audience consumption. We tracked the robust emergence of such contemporary disability arts in New York City, well known for embracing a range of artistry and activism. We met with and interviewed artists and activists, attended workshops, rehearsals, performances, and exhibits, and learned how to build access into the events that we organized at our university. Additionally, we documented accessible art practices that we came to understand as third spaces, projects that embraced the arts as a form of community building for people with developmental disabilities while rejecting art therapy models. Such under-the-radar efforts welcomed people with a wide range of disabilities as participants. The disability artistry that we were privileged to share demonstrated the world-making creativity central to the widening recognition not only of disability rights but also disability justice and its intersectional approach.[9] This latter framework emerged in the twenty-first century to contest a too-narrow focus on individual disability rights and insufficient attention to how disability is shaped in relation to other social categories—race, ethnicity, class, gender, sexuality, and religion—that are also subject to discrimination.

Our research coincided not only with an explosion of a range of disability arts in the city; it also overlapped with the global spread of COVID-19. When New York City became the epicenter of the US pandemic in March 2020, there was a rapid shift to remote platforms that made disability arts dramatically more available, including the online events that we programmed at NYU. This embrace of the virtual offered a COVID-induced silver lining for many disabled artists and audience members for whom mobility, accommodations, and inclusion are challenges in the best of times. Along with our colleague Mara Mills, who codirects the Center for Disability Studies with Faye, we were awarded a National Science Foundation grant that enabled us to organize a research team to query how people with diverse disabilities were managing the challenges of the pandemic (Ginsburg, Mills, and Rapp 2020a, 2020b, 2022; Mills et al. 2024a, 2024b).

Adventures on the Möbius Strip

Throughout the fieldwork we have been chronicling, our intellectual scaffolding built on essential methods and theoretical approaches in anthropology, disability studies, and feminist theory, deploying overlapping traditions of these distinct but related fields. All these approaches draw on reflexivity as a foundational method, acknowledging that researchers' experiences shape the epistemology and analysis of any study in which they are engaged. As in all reflexive studies, our existential circumstances—age, gender, sexuality, religion, race/ethnicity, familial status, education, class, historical location, generation, and more—inevitably influence our approaches to fieldwork and how interlocutors respond to our presence in their lives. As cultural anthropologist Barbara Myerhoff explained succinctly at a time when reflexivity was newly influential, this self-aware approach is essential as ethnographic fieldwork requires that the self is the instrument of data generation (Myerhoff and Ruby 1981, 18).

Our increasingly reflexive involvement in our research has had a profound impact on us in several ways. We continue to find ourselves caught up in the projects we are studying, at times taking an active role in enabling the very activities we examine. As a result, we dubbed our work "adventures on the Möbius strip," a reference to the intriguing nineteenth-century mathematical figure that features a looped surface with a half twist in which the inside and outside are seamless and indistinguishable (Gunderman and Gunderman 2018). This form captures the vertiginous sense of traversing a shape-shifting territory that we are exploring through interdependent ties of kinship and caregiving as well as our collaborative observant participation, writing, teaching, mentoring, and advocacy.

Disabled people are justifiably suspicious of outside "experts" pronouncing on and too often pathologizing their circumstances. From the outset of our research, we have taken our cues from our children and the many advocates we have encountered in this project; becoming and being an ally is always an ongoing and sometimes fraught process, not only in designing research methods but in building opportunities for disability worlds to expand. We are mindful of the complex role that parents can play not only as allies but also as obstacles (Carey, Block, and Scotch 2020).

As professors at a large university that historically had no disability studies program, we had ample opportunity to work as allies. In 2007, we mobilized a university-wide network, the NYU Council for the Study of Disability. It provided a platform to meet and work with students and colleagues with similar interests in disability studies and justice across the wide range of disciplines and schools that NYU encompasses. We sponsored public events with disability activists and scholars, provided campus meeting space for LD and autistic self-advocates and activists, created university affiliations for disabled artists, and hosted a pilot transition program for students with learning disabilities finishing high school.

In 2010, Mara Mills, an outstanding disability studies scholar specializing in the history of science and technology, joined the faculty at NYU and enriched our partnership in these emerging initiatives. With support from the administration, we created a working group in 2016 to address the profound needs for a more accessible campus. We also launched an undergraduate disability minor, bringing together colleagues distributed across disciplines and campus locations, from arts and sciences to engineering, to the film school, media studies, and education. In 2017, a provostial grant enabled Faye and Mara to establish and codirect the NYU Center for Disability Studies, at last providing a substantial campus presence for these long-standing efforts. Coteaching our disability studies core course for the first time in 2017 to eager and diverse undergraduates was a transformative experience for us, revealing the dynamism of post-ADA generations sensitized to disability issues. We found that our students understood the value of this work far more quickly than many of our faculty colleagues and peers. They taught us to embrace our role not only as allies but also as "accomplices" who can "enact social justice from positions of privilege" (Clemens 2017). They frequently asked us why work on disability is not being recognized as a fundamental topic in anthropology, given that the experience of disability, however defined, is a fact of life in every culture. Clearly, the significance of disability was not lost on them; many identified as disabled, perhaps because they were raised in a world in which disability was increasingly accepted and part of their familial lives at home, in schools, and in the public sphere. Unlike our own experiences growing up before the establishment of civil rights and cultural inclusion for people with disabilities, our students took for granted the aspiration for disability inclusion and justice.

Our home discipline of anthropology provided us with robust intellectual traditions rooted in the epistemological balancing act of "observant participation" as a method for understanding the kind of relationships we were both experiencing and studying (Moeran 2009). The reversal of terms for the standard ethnographic method of participant observation underscores our stakes in the world we have been researching, given that we have been deeply engaged in the lives of our adult children as well as in the broader disability community. Along similar lines, some American anthropologists have coined the term "engaged anthropology" to capture a sense of participatory research paradigms that extend from alliance to activism (e.g., Low and Merry 2010; cf. Rapp 2001), accompanying burgeoning work in "collaborative anthropology" (Haviland 2017; Lassiter 2005). All of these approaches are indebted to earlier disciplinary legacies of applied, action, and advocacy projects. Building on filmmaker and anthropologist Jean Rouch's (2003) practice of *anthropologie partagée* (shared anthropology) and beyond, more recent efforts to decolonize the discipline have also influenced our approach to research on disability.[10]

In 2018, we organized a Wenner-Gren international symposium on disability and anthropology, resulting in a special issue, "Disability/Anthropology," that we edited for *Current Anthropology* (2020). In the lead article of that issue, anthropologist, disability scholar, and activist Devva Kasnitz (2020) asked why anthropology had been so resistant to incorporating this topic, a concern she has articulated for decades: "Anthropology's institutions have failed to embrace disability studies despite the feminizing, browning, queering, and now the cripping of anthropologists. Perhaps this is because for some, these developments, like applied anthropology, suggest a loss of status for the discipline. How can we think about the decolonizing of disability given the historical resistance to the topic in our discipline?" (s17). A younger generation of anthropologists is increasingly receptive to the significance of disability, expressing rejection of the unspoken ableism of the field. Following Kasnitz, Erin Durban offers a powerful critique of the marginalization of disabled anthropologists and the need to radically reimagine the discipline's romance with "heroic fieldwork" from undergraduate training to grad school to hiring and promotion practices in the academy. Durban's 2022 article, "Anthropology and Ableism," published in the discipline's flagship journal, makes this position clear:

> Ableism is inherent to anthropology's disciplinary formations—especially expectations pertaining to fieldwork. . . . The continuation of fieldwork practices from the colonial model naturalizes able bodyminds, and without intervention, reproduces ableist anthropology. . . . A line was solidified between "anthropologist" and "the disabled," thereby making disabled anthropologist a seemingly conceptual impossibility. The effect of the anthropological gaze turning towards disability introduced a "corporeal unconscious" . . . ; the specter of becoming disabled . . . haunts fieldwork and heightens the anxious relation of anthropology to disability. . . . Of all people, anthropologists should understand the advantage of having a multitude of perspectives from which to continually think and rethink together. (8–11)

In the wake of these well-deserved critiques, disability is gradually entering the discipline in the twenty-first century, building on a small but nonetheless significant legacy of earlier scholarship (Ginsburg and Rapp 2013, 2020b). Increasingly, anthropological research and publishing more routinely include outstanding ethnographies focusing on the wide-ranging experiences of disability in diverse cultural locations. The acknowledgment and embrace of critical disability studies and disability justice perspectives by an increasing number of anthropologists also entails an ongoing reflexive understanding of the research/activism nexus, as we learned over and over in our own efforts.

In other words, work in this area invokes many of the same commitments to nonextractive collaborative research practices that have characterized initiatives to decolonize anthropology as well as disability studies (Hartblay 2020b; Imada 2017; Kasnitz 2020).

Our discipline's professional association, the American Anthropological Association (AAA), has been the site of an enduring struggle by and for disabled people demanding access in meetings, publications, and projects. The AAA Disability Research Interest Group (DRIG) has long been hosted by the association's Society for Medical Anthropology, which carefully clarifies that hosting DRIG does not make disability a medical topic. Along with other DRIG members, we waged a prolonged battle for an ombudsman position, welcoming the first accessibility and meetings coordinator in 2020 with great enthusiasm (Perez and Koneczny 2022). These battles have yielded results. While access is always a work in progress, AAA events—on- or offline—now include affordances such as audio and image description, CART (captioning access in real time)/live transcript, and American Sign Language interpreters as well as revoicers on request.[11]

Encountering Disability Worlds: An Overview of the Book

This book loosely follows our journey over the last few decades. Initially, as parents of newly diagnosed children, we constantly faced efforts to test and stratify our own and other children's cognitive differences. These ranged from genetic screening and experimental brain research to medical forms and "special education" paperwork, a classic Foucauldian governmental project of sorting populations. Yet, at the same time, we also encountered and joined a lively, expanding cultural counterpoint in the work of disability advocates and activists, struggling to democratize and valorize neurodiversity. In chapter 1, "The Doubled Telos of Modernity: Genetic Screening, Atypical Brains, and Neurodiversity," we explore a tension that is foundational to the complex biopolitics shaping disability worlds in the current neoliberal era, offering contrasting imaginaries of collective social life in the present and near future. To understand these seemingly contradictory approaches, we began fieldwork with people engaged in diverse cultural projects that collectively exemplified this tension, ranging from science to self-advocacy. We first located ourselves at genetic testing clinics where we observed the expansion of neo-eugenic discourse shaping prenatal testing. Later, we also conducted fieldwork in pediatric neuroscience labs carrying out brain research with children diagnosed as atypical in order to locate biomarkers that might eventually lead to therapies. Both sites are governed by foundational scientific ideas of human improvement and perfectibility. By contrast, we also worked with organizations founded by disability activists seeking creative interventions in the biopolitical landscape. We attended Autistic Self-Advocacy Network's public events and established a working alliance with the college student–led group Eye to Eye. Together, these sites reflect distinct regimes of the scientific and the celebratory. The aspirational inclusion of disability as a social fact that activists champion is thus in tension with the drive toward an imagined and stratified biomedical utopia that fuels medical innovation and intervention intended to fix, cure, or eliminate disability.

In chapter 2, "New Kinship Imaginaries and Their Limits," we chronicle how disability transforms family life as disabled kids move through the life cycle. Their atypical experiences reverberate through their families, reframing taken-for-granted assumptions about kinship, normalcy, and caregiving. Like many of the 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. Along with our interlocutors, we came to challenge the unproblematic linearity of the standard life course and the routinized pace of everyday events. In short, our kids taught us to learn to live on crip time, a now widely used term among disability activists and scholars to signify the distinctive time, energy, and resources needed by people with disabilities in an ableist world. Disability writer Ellen Samuels (2017) underscores that crip time can also encompass the grieving experienced with each new impairment and the lost time that it entails, while Emma Sheppard asserts that crip time "must include . . . time to be unsure, ambivalent about disability, and time to mourn future possibilities that can no longer be" (2020, 45). In this chapter, we focus on families—biological and/or chosen—with cognitively atypical school-age children; as those children and our own grew, our research evolved to incorporate the difference of disability across the life course and to include the experiences of parents with disabilities as well. How, we asked, do these particular aspects of living with disability provoke a rethinking of the intimate world of kinship? Beyond the unrelenting quotidian work involved in creating accessible domestic space, struggling to obtain services, locating and sustaining opportunities for social inclusion, and juggling therapeutic treatments and appointments, there is the existential project of embracing and insisting on the full humanity of a disabled family member. These aspirations and actions—enacting what some call "crip kinship" (Kafai 2021)—push back against the unspoken but pervasive symbolic violence and psychic damage produced by the taken-for-granted ableism that persists despite legislative victories. Overall, this chapter explores how new kinship imaginaries create alternative possibilities that reverberate into building accessible futures (Kafer 2013) for disabled people and their supporters.

In the context of schooling, by necessity, many parents move from a sense of isolation as they join with like-minded others, becoming persistent, vigilant advocates for their children's diverse pedagogical and social needs. In chapter 3, "The Paradox of Recognition and the Social Production of Moxie," we discuss how labeling is bureaucratically produced; in response, resistant advocates are made, not born. While educational supports are often essential to a struggling child's progress, they are not available without a bureaucratic label. Yet the label itself may have lifelong consequences; stigmatizing tags can be hard to lose. This is what we call the paradox of recognition. We draw attention to the process we witnessed time and time again as parents, and especially mothers, learned to master the tasks necessary for managing the complexities of the "special education" universe. Parents are interpolated into being their child's advocate, both to enforce their legal rights and to protect them—when possible—against the bullying this recognition too often entails. Their hard-won disability expertise and necessary activism impressed us as moxie. Without parents' willingness to challenge conventions and their lively insistence on their children's potential capacity—in short, deploying what we call moxie—this story of the paradox of recognition rarely ends well.

Unlike in past generations, young people with cognitive disabilities now routinely attend school alongside their peers without disabilities. Yet once they leave school, many with developmental disabilities find themselves "Transitioning to Nowhere," the title of chapter 4, describing the fate of many thrown into an underfunded and uncoordinated system after high school in which few services are available as a matter of right. We learned from our own experiences and those of our respondents that the state of transition to life beyond secondary schooling, a routine rite of passage for the nondisabled, is often a crisis for those with disabilities. Yet fieldwork with the innovative transition experiments that we discuss in this chapter also offered utopian glimpses into what might happen if students with disabilities were actually recognized as transitioning to somewhere. One particularly original approach was invented by a group of LD college students with whom we worked; members of this growing organization, Eye to Eye, "came out" about their shared experiences of living creatively with cognitive differences. They were dedicated to finding ways to make the road easier for generations of young LD students to follow and now have a widespread national base. Additionally, programs in alternative higher education for cognitively disabled students, from early and enduring experiments that started in the 1980s to recent initiatives such as Think College, have begun to open doors to higher education for a broader range of people with intellectual disabilities for whom tertiary education was unavailable until quite recently.

Chapter 5, "Living Otherwise: Worlding Disability Arts," tracks the histories and everyday practices of the disability arts activists we encountered first as parents of children with disabilities, then as fans, allies, and scholars/advocates. New York City is famous for embracing a broad range of innovative artistry and activism, and disability arts is no exception to this deserved reputation. We explored a wide range of projects created by people with various bodyminds across a dizzying array of genres, including film, dance, painting, performance, music, and theater works. Collectively, they are producing new cultural imaginaries centered on disability experiences and aesthetics, reframing the very concept of artistry itself. The disability art world, like all sociocultural worlds, is diverse, ranging from community theater in city parks and poetry readings in neighborhood libraries to disability arts boot camps at cultural institutions such as the Whitney Museum and the Gibney Performing Arts Center, drive-in film screenings, dance at Lincoln Center and the Shed, and performances on Broadway and on the High Line, to name a few of the venues where we witnessed this florescence. Our ongoing research both preceded and coincided with the COVID-19 pandemic, when many activities had to shift online, creating unexpected challenges and opportunities for those engaged with the disability arts world. We met with and interviewed artists and activists; attended workshops, rehearsals, performances, and exhibits; and organized events at our university, learning again and again how participation in the arts offered new opportunities, resources, and models for living otherwise.

Chapter 6, "Disability Worlds / Disability Futures," returns to the question of "accessible futures" raised by Alison Kafer (2013). We first turn our attention to the ever-expanding disability demographic and its social and political importance now and in the foreseeable future: Looking forward, how do we both "count disability" and "make disability count" (Ginsburg and Rapp 2015a)? In pursuing this question, we turned to demographers to understand "the epistemology of numbers" governing their efforts to track the growing and always unstable category of disability. Their measurements have important consequences, informing the emergence of disabled people not only as the largest minority in America with rights to resources and entitlements. They are also the underappreciated "ticking time bomb of the electorate," to use the compelling phrase offered by lawyer/historian and disability activist

Rabia Belt (2016). Following her lead, we track the recognition of "the disability vote" since the 1960s and the formation beginning in 2016 of activist groups that mobilized to "make disability count" in electoral, and especially presidential, campaigns. We also consider how the growing numbers of disabled people intersect a long-standing crisis in caregiving that became more acute during the pandemic, presaging increased future need. Finally, we returned to some of the families who had initially helped us understand how they were reshaping daily life and kinship imaginaries with their disabled children, now adults, many living at home as their support systems were deeply challenged by COVID-19. The pandemic accelerated their fears, given the precarity of services over the life course, while also motivating action to remediate the anticipated free fall from what has come to be known as the disability cliff, when disabled young adults age out of their school entitlements. In short, we consider how meaningful disability futures are both enhanced and challenged in public domains as well as in intimate circles of crip kinship.

Conclusion

In writing this book, we have chronicled our personal journeys as nondisabled parents encountering disability worlds in New York City with our growing children. Along the way we learned (and continue to learn) what disability activist and scholar Rosemarie Garland-Thomson (and many others) taught us about "becoming disabled":

> Disability is everywhere once you start noticing it. A simple awareness of who we are sharing our public spaces with can be revelatory. Wheelchair users or people with walkers, hearing aids, canes, service animals, prosthetic limbs or breathing devices may seem to appear out of nowhere, when they were in fact there all the time. . . .
>
> Becoming disabled demands learning how to live effectively as a person with disabilities, not just living as a disabled person trying to become nondisabled. It also demands the awareness and cooperation of others who don't experience these challenges. Becoming disabled means moving from isolation to community, from ignorance to knowledge about who we are, from exclusion to access, and from shame to pride. (2016)

We also learned from the critical disability and race studies scholar Nirmala Erevelles about "disability as becoming": when "impairment is no longer merely a biological fact, but is, instead, a manner of becoming-in-the-world that reorganizes lived space and time as well as the social relations between the self and other bodies" (2011, 36). These lessons were taught to us again and again as we carried out fieldwork with a wide range of extremely generous and thoughtful research participants and their projects, highlighting Garland-Thomson's insistence that "disability is everywhere once you start noticing it."

Along with the families we came to know, we encountered both blocked pathways and visionary innovators giving shape to the possibilities of disability justice. We were fortunate that our research intersected the burgeoning of disability arts, centered in New York City, providing an exciting sense of possibility, reflecting the wisdom of the late disabled artist Neil Marcus's words: "Disability is not a 'brave struggle' or 'courage in the face of adversity.' Disability is an art. It is an ingenious way to live" (Block et al. 2016, 360). We concur. Our engagement with our children over the decades, along with a wide range of disability advocates and activists, has shown us the necessity and possibility of building disability worlds. More is yet to come.

Notes

INTRODUCTION

1 The Familial Dysautonomia Foundation website states:

> Familial Dysautonomia (FD) is a genetic disorder that affects the autonomic and sensory nervous systems. Though FD affects people across the world, it occurs almost exclusively in children with Ashkenazi Jewish heritage. FD is one of the rarest of diseases, with only 300 people currently living with FD worldwide.
>
> FD is inherited in an autosomal recessive manner, when both otherwise healthy parents pass on their copy of a mutated IKAP gene. . . . Infants are born unable to sense information coming from inside their own bodies. All the normal bodily functions we take for granted are . . . awry in people with FD. Perhaps the most striking symptoms of FD are . . .
>
> - Insensitivity to pain
> - Unstable blood pressure and body temperature
> - “Autonomic crises:” Episodes of cyclical vomiting accompanied by extremely high blood pressure and increased heart rate, sweating and fever
> - Absence of tears
> - Poor growth
> - Other respiratory, cardiovascular, orthopedic, digestive, and vision problems
> - Inability to suck or swallow. Many individuals affected by FD must use feeding tubes to receive proper nutrition.
>
> Living with FD is a daily challenge filled with unimaginable obstacles for those who are affected as well as their families. (Familial Dysautonomia Foundation, n.d.)

2 In their book *Loneliness and Its Opposite*, anthropologist Don Kulick and gender studies scholar Jens Rydström offer both an appreciation and a critique of the term *crip*: “Crip theory has helped refresh disability studies as a field of research . . . [that is] theoretically innovative, and even sexy. But even as one acknowledges that, one can be skeptical about its usefulness as an analytic perspective . . . [particularly for] people who have little or no verbal language, who do not engage in cultural critique, or political activism, who live in institutions or group homes, who require a great deal of assistance to manage basic activities like eating or communicating and getting by in their day-to-day lives” (2015, 14, 15).

3 We place “special education” in quotation marks throughout this book, attending to critiques of that term despite its continued use in everyday speech, educational settings, and the law. David Connor and Beth Ferri (2010) point out that “special education continues to offer hope to many families whose children with disabilities who—prior to 1975 when local schools were federally mandated to educate *all* children—were completely excluded or placed in institutions. . . . However, special education continues to be marked as a site of racial segregation in schools, stigma, inadequate curriculum and low expectations including its association with the ‘school-to-prison pipeline.’”

4 In developing the concept of disability worlds, we acknowledge the pathbreaking work of Belgian anthropologist Patrick Devlieger and associated European scholars. They convened DISABILITY MUNDUS (Latin for *world*) in 2012, “to support research efforts on disability with a focus on the European continent”; the concept unified *Rethinking Disability: World Perspectives in Culture and Society* (Devlieger et al. 2016). DISABILITY MUNDUS “has the potential to create transformations, offering the radical presentation of disability as a resource, and a creative source of culture, that moves disability out of the realm of victimized people, or as an insurmountable barrier. [Rather,] the experience of disability provides the opportunity to enter into networks that recognize strengths of different abilities and that include considering resilience, survival, vulnerability, body knowledge, and performativity as resources” (Devlieger et al. 2016, 19).

5 In their illuminating memoirs, the late disability activist Judith Heumann and disabled artist/activist Riva Lehrer offer remarkable first-person accounts of their struggles in the pre-IDEA era before disabled children had educational rights. They recount their mothers’ heroic efforts, insisting that their daughters receive an education. Judith Heumann was barred from attending school—public or religious—with her siblings or peers in Brooklyn; her parents refused to send her to an inadequate school segregated by ability. The NYC Board of Education provided only very limited home schooling. She writes, “I wasn’t expected to be part of the world. . . . I was a butterfly becoming a caterpillar” (Heumann and Joiner 2020, 14). By contrast, in Cincinnati, Riva Lehrer was fortunate to attend the unusual Randall J. Condon School, named after a superintendent with “a radical philosophy: that disabled children should receive a standard academic education. At that time [1963], most schools for disabled children were residential warehouses” (Lehrer 2020, 31). While the Condon school was segregated for disabled students only, the quality of the education was high, including an art curriculum that was foundational to Lehrer’s career as an artist.

6 The number is now 61 million, approximately one in four Americans (CDC 2023).

7 See Mobilization for Justice, https://mobilizationforjustice.org/.

8 See Think College, https://thinkcollege.net/.

9 Disability justice emphasizes the intersections of disability and ableism with other forms of oppression and identity like race, class, gender, sexuality, citizenship, incarceration, size, and so on. It was launched in 2005 by the Disability Justice

Collective, a group of Black, brown, queer, and trans people including Patty Berne, Mia Mingus, Stacey Milbern, Leroy F. Moore Jr., Eli Clare, and Sebastian Margaret, all connected through the group Sins Invalid, a disability justice–based performance project that incubates work by disabled artists ("Disability Justice" 2022; Sins Invalid 2015).

10 "Decolonizing anthropology (at a minimum) has now grown to a project beyond its initial impetus in treating non-anthropologist intellectuals as just that: intellectuals rather than local interlocutors. In its development across the discipline . . . decolonizing anthropology is a project about rethinking epistemology, methodology, community, and political commitments" (McGranahan and Rizvi 2016).

11 Audio description refers to the verbal explanation of key visual elements in media and live productions, providing information on visual content that is considered essential to understanding the material. A revoicer supports someone with a speech impairment, using a variety of cues including lipreading to understand and repeat the speaker's utterances, for easier audience understanding.

1. THE DOUBLED TELOS OF MODERNITY

1 In 2004, the American College of Obstetricians and Gynecologists added screening for FD to its standard of care. For the history of FD and genetic screening, see Lerner (2009).

2 America's widespread if uneven genetic screening contrasts with more restricted testing in France and some other European countries, where the influence of both the Holocaust and the Catholic Church are extensive (Ginsburg and Rapp 2020b).

3 Prenatal Preparation: Actions and Results (PREPARE) is the first empirically grounded national study examining prenatal preparation for children with genetic conditions, building a model of how pregnant women, families, clinicians, and support groups access resources for those continuing pregnancies after a positive diagnosis (Michie 2019, 2020).

4 Sinclair founded Autism Network International with self-advocates Kathy Grant and Donna Williams, who authored the groundbreaking memoirs *Nobody Nowhere* and *Somebody Somewhere* (Williams 1992, 1994). In 1999, UK activist Larry Arnold launched Autistics.org.

5 Singer's (1999) work on autism and neurodiversity became widely known through her essay "Why Can't You Be Normal for Once in Your Life?" followed by her 2016 book, *Neurodiversity: The Birth of an Idea.* In 2023 she published an anti-trans tweet that created considerable controversy; she deleted it in response. This has tarnished her reputation among many disability and autistic activists (Rao 2023).

6 We thank anthropologist Cara Ryan for introducing us to many critical neurodiversity resources.