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Collaborative Research on the Möbius Strip

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Introduction

Our collaborative writing is based on an enduring friendship and feminist academic partnership long preceding the diagnoses of each of our children (discussed later). Their new labels catapulted us into what we came to think of as disability worlds, a territory we encountered as parents that was previously unknown to us as "underimpaired" mothers and anthropologists (Davidson 2015). Our family lives took on new and unanticipated temporal trajectories with our children, including long stretches living in hospitals, endless searches for appropriate services and educational settings, and evenings and weekends devoted to supplemental tutoring and therapeutic regimens. In short, we were operating on what we later understood to be "crip time" (Kafer 2013). Additionally, we found ourselves reinventing family life with a difference, a process we recognized in other "disabled families." Eventually, after years of research described below, we came to understand that we and many others were forging "new kinship imaginaries," the creative transformations that families perform when disability catalyzes a departure from the typical normate life course. As for all mothers and others living in such disability worlds, an embrace of interdependence was crucial to our collective survival, an understanding prefigured in our feminist roots. These essential insights propelled our joint scholarship toward what we now think of as "cripping reproduction."

Our work started with our shared interests in the complexities of women's experiences of reproduction from the abortion controversy (Ginsburg 1998) to the rise of late twentieth-century reproductive technologies (Rapp 2011) as sites of constant contestation in American cultural life. In 1991 our first coauthored article on "the politics of reproduction" appeared in the *Annual Review of Anthropology* (Ginsburg and Rapp 1991), followed by a conference sponsored by the Wenner-Gren Foundation for Anthropological Research that we organized on that topic and a subsequent edited volume, *Conceiving the New World Order: The Global Politics of Reproduction* (Ginsburg and Rapp 1995).

The roots of our collaboration grew deeper and increasingly interdependent when a pregnant Faye served as a research subject for Rayna, who was then in the midst of her study of women's experiences and decision-making around amniocentesis genetic testing and the possibility of having an atypical fetus. It is an enduring irony of our long-standing research and writing partnership that when Rayna asked Faye back in 1988—when there were only a limited number of genetic tests available—how she felt about being the subject of such testing, she replied, "Well, now I know my fetus doesn't have three things wrong with it. And for the rest, we'll see." When her daughter Samantha was born a few months later, she had mysterious and life-threatening symptoms that landed Faye and Sam in the hospital for months on what medical anthropologists call "the diagnostic odyssey." At six months, Sam was diagnosed with a very rare autosomal recessive degenerative Ashkenazi Jewish genetic disorder, familial dysautonomia. From that point on, the two of us have been in a constant entangled conversation regarding the gaps between existential, cultural, religious, and biomedical understandings of what life with a difference—disability—is all about (Ginsburg and Rapp 2013).

Eight years later, Rayna's second child, Teo, was diagnosed with significant learning disabilities in his early school years. Our children went to the same "special ed" primary and middle schools, and we kept the conversation going about what it meant for them to live with disability as we navigated the labyrinth of bureaucracies necessary to procure the services to which they were entitled. Dealing with all the issues we faced, along with our kids—severe medical problems for Sam, and stigma faced by both—strengthened our teamwork: fierce advocates for our children, "accidental activists" (Panitch 2007) in our communities, engaged autoethnographers, disability studies scholar-advocates, and inseparable writing partners. Over the next decades, by necessity we followed the path of so many other parents of kids diagnosed with various chronic conditions—from learning disabilities to genetic disorders—as we sought support for our children and their alternative ways of learning about and engaging with the world. 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 with the City of New York to secure funding for appropriate accommodations. Faye found that Samantha's familial dysautonomia affected her learning style, as well as causing a panoply of other, more severe complications that ranged from feeding tubes to the need for mobility support. Like most parents who discover that their kids need "special education" services, we were at first absorbed in a new reality for which we were utterly unprepared at both the pragmatic and existential levels. We dedicated ourselves to learning about our children's particular issues and locating educational settings and services that would meet their diverse needs. As close friends and longtime research partners, we were engrossed in constant discussion as we tried to make sense of our discoveries. The feminist motto "The personal is political" was our North Star.

In 1999, our essay entitled "Fetal Reflections: Confessions of Two Feminist Anthropologists as Mutual Informants" highlighted our growing concern that understanding the implications of a diagnosis of disability was thoroughly segregated from women's decision-making about prenatal testing (Ginsburg and Rapp 1999). How, we wondered, could potential parents possibly make an informed decision about whether 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 family member with a bodymind impairment (Price 2015; Schalk 2018)? We began to write about these distinct discursive arenas as siloed "social funds of knowledge," segregating genetic diagnoses and "disability expertise" (Rapp and Ginsburg 2001; Hartblay 2020) that, we insisted, must be considered together. We began writing and teaching about the consequences of that segregation of knowledge, discovering that disability awareness and the practice of genetic testing—which both had escalated dramatically over the last few decades—were rarely brought into the same conversation. Ethical reflection in the realm of biomedicine, we found, is obscured in quotidian events such as the signing of routine consent forms where issues of the inclusion and exclusion of diverse bodyminds are too readily silenced.

We grew increasingly concerned with the tensions between these two powerful but contradictory aspects of contemporary life, what we have called the "doubled telos of modernity," a phrase we invented to describe this apparent contradiction (Rapp and Ginsburg 2001). On the one hand, biomedical progress, particularly around assistive reproductive technologies, continues to hold out the deeply American, neo-eugenic promise of perfectibility, given that fetuses found to have anomalies through prenatal testing are decreasingly brought to term. On the other hand, the rise of the disability rights and justice movement has created a robust ethical and political framework for democratic inclusion across the full range of human variability. Increasingly, we understood that these different and seemingly conflicting imperatives were reshaping life in the twenty-first century but their connections were rarely recognized. In response, we started "cripping reproduction" in our writing, calling for a more productive dialogue between aspirations for neo-eugenic exclusions in genetic testing and broader disability inclusion.

Birthing a Research Project

Out of necessity, our practical knowledge and capacity to provide what disability activist, writer, and educator Mia Mingus (2011) calls "access intimacy" for our children expanded. With that term, Mingus is indexing "that elusive, hard-to-describe feeling when someone else 'gets' your access needs." Along with other scholar-activists, we learned how different bodyminds are shaped by medicalized stigma, social policy, public neglect, and, increasingly, activism and lively cultural innovation built on many years of prior advocacy. Immersing ourselves in diverse domains of disability experience, our collaboration deepened as ethnographers of each other's journeys. In the process we became increasingly interdependent, finishing each other's sentences, no longer aware of where one of our ideas began and the other's ended. Further, our access intimacy extended to accommodating each other'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. Sitting next to family members ordering Chinese takeout or receiving end-of-life counseling from a chaplain from their religious tradition, our conversations whiplashed between looking up alternative treatments and brainstorming our next article or presentation. Meanwhile, Rayna was sending 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, became our praxis. We came to understand and value that we were constantly operating on crip time, our pacing responding to the interruptions that interdependency demands. Our conversations—and minds—were melding, and we could no longer identify the source of our coproduced insights.

In 2006 we decided we were ready to go empirical. Although by then we had been writing together for over a decade, our first externally funded collaborative fieldwork project began the following year. We quickly discovered that research in New York City has locational advantages for ethnographers beyond our deep insider knowledge. The Big Apple is well known both for failed public support for disabled students in and out of school and for lively cultural innovation for people with disabilities in alternative education, the arts, and access to cultural venues. Further, the metropolitan area is famous for its broad spectrum of race, class, immigration, gender and sexuality, and religious diversity. In short, New York offers problems and possibilities that characterize the complexity of the experience of disability in the twenty-first century.

Our formal inquiry started with a foundational question that mirrored our own experiences: How do diverse families with a newly diagnosed child manage the logistics required to meet their youngster's school needs and social integration? Many informal encounters and conversations—in waiting rooms, on school playgrounds, and at community board meetings—enriched our structured interviews across New York's five boroughs with over fifty "disabled families" coming from diverse socioeconomic, cultural, ethno-racial, and religious backgrounds. All had children with learning differences requiring an individualized education plan, the federally mandated personalized roadmap outlining accommodations for each pupil diagnosed with a disability. We quickly learned that neither the children so labeled nor the label itself was easily domesticated or reified. "Learning disabilities," for example, was an often-fuzzy classification of disabling difference with its own genealogy, as it displaced profoundly stigmatizing terms such as "mild mental retardation," "minimum brain damage," and even "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 both the life course and the education system, balancing complex social situations—and sometimes medical diagnoses—and creating new understandings of family life. Their children, many of whom are now young adults and older, also increasingly became part of our conversations as they developed new understandings of what it means to live with disabilities and imagine "accessible futures" (Kafer 2013).

One of our earliest findings was that these families—and especially mothers—have been creating alternative kinship stories that reclaim their children from an exclusively medical diagnostic label as disability becomes a regular yet distinctive feature of kinship, domestic life, and public culture (see also Landsman 2009; Grinker 2021; Kittay 2019). With few available models for "life with a difference," they have produced story after story, what we think of as counternarratives. Often, these paralleled our own experiences cripping both reproduction and childrearing, imagined against the grain of conventional ideas of what constitutes appropriate parenting, a child's success and anticipated road forward, and expected cycles of family life. In other words, we began to recognize a particular sense of the present and future forged in dialogue with their children's differences as they drew their own roadmaps. We were not alone in tossing out typical child development books in favor of our hard-won knowledge of the roads less traveled. We have been writing about this shifting and more inclusive transformation as "new kinship imaginaries," reframing domestic lives lived with a difference (Rapp and Ginsburg 2001; Rapp and Ginsburg 2011). This paradigm shift—for ourselves and our interlocutors—often occurred as families realized their experiences didn't map easily onto preexisting models of American life. We were committed to writing about the radical potential of these stories to retrieve people with disabilities from the clinical framework of diagnosis and pathology. These collectively constitute an emergent terrain that encompasses the broad range of people whose narratives have been silenced until relatively recently. They also 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.

As our ethnographic research developed, we quickly realized that there is a yawning gap between the legislative promise of equity and inclusion for those with disabilities and the problematic realities most face: overwhelming bureaucracies, aging infrastructure, and ableist attitudes create enormous frustration, motivating parents like us to not only create new narratives but also, at times, undertake unanticipated action. We began writing about how this gulf between the legal mandate of inclusion and the reality of everyday discrimination was becoming the space of potential cultural transformation that interested us as both anthropologists and advocates. The activism on the part of many of our subjects across a broad range of backgrounds was particularly striking as they confronted the challenge of creating a more hospitable world for people with disabilities and their allies. Their experiences with disability turned many of them into accidental activists (Panitch 2007). As they learned about and demanded their rights, many developed new forms of courage and creativity, a process that we wrote about as "the social production of moxie" (Ginsburg and Rapp 2010). As one parent advocate put it, "The birth of our son with cerebral palsy brought the disability rights movement into our living room" (Habib 2008).

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 the subways. Others were bureaucratic and interpersonal, the kind of experiences we shared with our interlocutors. For example, families spoke indignantly of their run-ins with hostile educators who had mastered the fine art of counseling children with learning disabilities out of their public, private, and religious schools without directly saying they were not welcome. Clearly, the passage of legislation such as the Individuals with Disabilities Education Act and Americans with Disabilities Act were necessary but not sufficient steps to creating a disability-friendly world.

Over time, our writing, initially focused on families, schools, and the world of special education, became more capacious. Beyond the accommodations required by law to integrate people with disabilities into public life, we encountered remarkable creativity and diverse forms of cultural innovation. We plunged into the lively and unruly disability worlds inhabited by our interlocutors, exploring high school transition and alternative college programs, pediatric neuroscience and epigenetics labs, cultural activism in the arts, disability film festivals, and more. In short, our writing expanded to include the disability expertise of a wide range of respondents as we grappled with the complex questions raised by disability across the life course. The question of inclusion as well as social and infrastructural transformation hovered everywhere in our writing, as both utopian promises and a new normal. Over time we found again and again that the bureaucratic separation of disability categories—although a social fact—was contested in the emerging disability publics we encountered. What does it mean, we asked, to welcome all kinds of bodyminds, not only in schools but also in communities, places of worship, scientific and medical research, the arts and media, and ultimately American public life?

Adventures on the Möbius Strip

Our fields of disability and feminist studies, and our anchor in the discipline of anthropology, all share a long-standing embrace of reflexivity, encouraging us to theorize our own experiences as we navigated and wrote about the complex medical and educational bureaucracies as well as arts and politics that shaped our children's and family lives. We continue to find ourselves caught up reflexively in the projects we are studying, at times taking an active role in enabling the very activities we examine. This produces a sense of being simultaneously inside and outside the worlds we are exploring through interdependent ties of kinship and caregiving as well as our collaborative research, writing, teaching, mentoring, and advocacy. As a result, we have often experienced a vertiginous sense of our work as "adventures on the Möbius strip," in 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).

As with many other disability and feminist scholars and anthropologists, our increasing involvement in this work has had a profound impact on us in several ways. The people with whom we work have often recognized us as allies because of our shared situation as parents of now-adult children with disabilities who are active in the broader disability world. Our students taught us to embrace another role as "accomplices" who can "enact social justice from positions of privilege" (Clemens 2017).

As members of a university community, we sometimes have institutional resources to offer in support of our mutual culture-changing work, providing campus meeting space for autistic activists, creating affiliations for disability artists, hosting a pilot transition program for students with learning disabilities finishing high school, organizing a steady stream of disability events from film screenings to book launches, and addressing the profound need for a more accessible campus. We have been deeply implicated from the outset in observing, participating in, and writing about such ventures. Our status as activist parents, researchers, teachers, organizers, and writing partners has been crucial to our commitments and credibility in a world justifiably suspicious of outside experts pronouncing on and too often pathologizing the circumstances of people with disabilities.

This chapter has offered us the opportunity to reflect on the significance of collaboration in our work together as feminist scholars and disability activists mutually engaged in research, teaching, writing, and world-building over three decades, what we have come to understand as our partnership in crip authorship. Following the shape of our central figure of the Möbius strip, each of our projects loops experientially into the next, propelling a dizzying sense of transformation, anchored in our ongoing conversations. The collaborative writing that results, we argue, serves as a microcosmic model of the feminist interdependency that not only is central to our own work and lives but also intersects with the broader pursuit of disability justice.

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