http://dx.doi.org/10.1590/S0104-71832022000300012

Anthropology and disability: an interview with Rayna Rapp and Faye Ginsburg

Helena Moura Fietz[I]
https://orcid.org/0000-0002-6568-4760
helenafietz@gmail.com

[I] Rice University – Houston, Texas, United States

Introduction

Anthropologists Rayna Rapp and Faye Ginsburg have been contributing to anthropology's understandings of reproduction, gender, and disability since the 1980s. Rapp's (1999) book *Testing women, testing the fetus: the social impact of amniocentesis in America* and Ginsburg's (1998) *Contested lives: the abortion debate in an American community* have changed the field of Anthropology of Reproduction, as did their groundbreaking volume *Conceiving the new world order: the global politics of reproduction* (Ginsburg; Rapp, 1995). Faye Ginsburg is the David B. Kriser Professor of Anthropology at New York University where she founded and directs the Center for Media, Culture and History. Rayna Rapp was also a Professor of Anthropology in the same department, having retired in 2021. In 2017, they were co-founders of NYU's Center for Disability Studies with Professor Mara Mills. The Center is one of the outcomes of over two decades of research and work that opened the pathway for several anthropologists of disability that came with and after them.

In 2001, they published "Enabling disability: rewriting kinship, reimagining citizenship" (Rapp; Ginsburg, 2001). The paper is a landmark for the Anthropology of Disability and is the result of the authors' previous work on reproduction, kinship, and gender studies, as well as their personal experiences as mothers of disabled children that had to learn how to navigate an unknown social landscape. They asked why information on disability was so scarce and how come families, and mainly women, had to face the moral and practical consequences of deciding where to continue a pregnancy or not, how to raise their disabled children, and how to make sure their lives were as good as the next persons. Since then, with research based in the US, they have explored how disability shapes and is shaped by kinship imaginaries, public policies, biomedical and legal actors, and public representations of disability in a longitudinal work that has accompanied changes in legislations, technologies, public and scholarly representations of disability, and the growth of the "emerged field" of disability studies.

Since then, they have not only published extensively on disability and anthropology, but have worked towards calling attention to the importance of disability in thinking through fundamental themes in anthropology, such as kinship, reproduction, personhood, and temporality. In 2013, they published the paper "Disability worlds" (Ginsburg; Rapp, 2013) in the *Annual Review of Anthropology*, tracing the historicity of disability within the field, and arguing that disability should be foundational to anthropology. A work that was further explored in the 2020 organized volume of *Current Anthropology* of the same name (Ginsburg; Rapp, 2020) based on a Wenner-Gren Foundation International Symposium held in 2017. They have just completed a new book exploring different facets of over 20 years of research dedicated to an Anthropology of Disability, to be published by Duke University Press.

I met Rayna Rapp and Faye Ginsburg over Zoom in June 2021 for an interview about their extensive work on disability. It is no surprise, then, that it turned out to be a three-hour-long conversation about their trajectories, the various ways in which "the personal is political" and academic, and the present, past, and future of disability research within anthropology.

On September 25, 2022, Samantha Ginsburg Myers, Faye's daughter and Rayna's life-long friend, passed away. In her 33 years, Sam touched the lives of many with her kindness, love, sense of humor and fierce advocacy on behalf of those with Familial Dysautonomia. Her legacy goes on through those who knew her and the work of those of us she has affected, even if indirectly. Thank you, Sam.

Interview

Helena Fietz: You wrote your first essay together in 1991 and it's been 30 years of you working together while also developing individual projects. Could you talk a bit about your trajectory, how it all started.

Rayna Rapp: Faye and I met when she was a graduate student, and I was a newly minted Ph.D. assistant professor. I gave a talk which would have been about gender and anthropology. My usual opening question: where are the women? Where is gender as the central social relationship in everything from kinship to politics to economy that anthropology studies? We started talking and, long story short, Faye put me on her Ph.D. committee and we kind of never stopped talking after that. When I started to do my research on amniocentesis, I went with Faye to her amniocentesis medical appointment. By 1988, I was launching that book[1] and working on amniocentesis and reproductive technologies and genetics as part of medical anthropology, but with a feminist lens. I went with Faye and we made a lot of jokes and annoyed the radiologist. It all would have been quite funny except that Faye and Fred's child was born with a very significant and very unusual disability. And that meant we were kind of attached at the hip not only on reproductive technology but on learning the ropes of disability. And from my point of view, I then just kind of became the extended family to try to understand how to make a good life for Samantha, who was going to develop in unusual ways, but Faye you should take over.

Faye Ginsburg: When Rayna came and gave that talk at the Graduate Center, you should understand she actually changed my life. It was right around the time Ronald Reagan got elected, so between the horror of that event and realizing where politics were going and hearing Rayna talk about feminist anthropology and looking at gender I got very interested in the right to life movement and the division among women around abortion. It's a political problem, but also an intellectual problem because while feminist theory insisted that "we should take seriously women's lives and beliefs", there were exceptions to that idea – right-wing women – and I thought, well, I'm going to go find out what's going on. Of course, I immediately wanted Rayna to be on my committee because I had some excellent people, but nobody who took feminist anthropology to the level that we needed. We were very bound at the hip from that point on and in a way reproduction and disability are very intertwined around that issue. Not in a way: they are. Before I ever thought about disability, I was really thinking much more about reproduction, but it really erupted from that same place for me. Of course, following Rayna's work on genetic testing, and then being her research victim. My daughter Samantha was not just born with a disability but born with a genetic disorder, Familial Dysautonomia (FD), that catalyzed families who organized themselves to raise money and awareness, working with medical specialists and scientists, what has become the usual kind of story in the genetic disease world. It was 2001 before we found the mutation that causes FD, making a prenatal genetic test available. When

---

[1] *Testing women, testing the fetus: the social impact of amniocentesis in America* (Rapp, 1999).

I went for an amniocentesis in 1988, there were only a few specific conditions that could be tested and virtually no discussion of the existential question that really has no answer: had knowledge of Samantha's condition been available to me at that point, what decision would I possibly have made in the absence of understanding what it would mean for her to live with FD? That stimulated the very first thing we wrote in 2001 after "The politics of reproduction":[2] "Enabling disability: rewriting kinship, reimagining citizenship."[3] The emerging technology of genetic testing was kept separate from the social fund of knowledge around disability placing pregnant women in a difficult position that Rayna calls *moral pioneers*. That's kind of where we started, the first bits of writing that brought those two streams of our work together. But we should go back to the politics of reproduction. Over to you, Rayna.

Rayna Rapp: At some point, we understood that we were looking at what we came to call "the politics of reproduction." Not just power, not just reproduction as a biological act, which had been sidelined in anthropology, or reproduction as norms, as in Couvade or that pregnant woman should do the following random 16 rituals in some group or another. Rather, there was a huge amount of power involved in having, coercing, giving or withdrawing the resources for women's reproduction, along with their allies in families or communities, in religious groups, in their schools. The politics of reproduction was an optic to focus on something that was very important that had been hiding in plain sight. To our surprise, when we spoke about the politics of reproduction, people asked: what happened to feminism? Where are the women? The answer was: they're at the center of this if you drag reproduction to the center of social theory. That became an organizing principle for a Wenner-Gren International Symposium (1991), and the edited volume that followed, *Conceiving the new world order: the global politics of reproduction*[4] and a whole bunch of other projects that we did. But it was definitely part of insisting that the feminist concern which had led us to reproduction as an optic onto a much wider screen

---

[2] Ginsburg and Rapp (1991).

[3] Rapp and Ginsburg (2001).

[4] Ginsburg and Rapp (1995).

was something that had to be understood as central to anthropology, not just a women's issue.

Faye Ginsburg: We tried to show reproduction's centrality in our individual projects, the fact that Rayna was forging research into the social impact of genetic testing, and I was deep into the politics of abortion.

Rayna Rapp: Right, we started to understand that our projects were opposite sides of the same coin. One of your questions had to do with the *doubled telos of modernity* which we came up with in 2001 or something. That's an attempt to make a social theoretical synthesis of what we're talking about, the siloing, the segregation and the suppression of knowledge about disability is not unrelated to the way in which you can then talk about perfectibility through medicine and reproduction. Whether it's public health or it's the idea that you could intervene with a genetic test or with anything else. Some of that intervention is stuff that enables people to thrive better like NICU and incubator technology. But some of it is part of the elimination of disability under the guise of making life perfectible or better through medical attention. I of all people am not saying don't use this technology, but I am saying that if you keep that knowledge siloed, that kind of disability expertise (as later younger scholars put it), if you keep them segregated or separate, it's a convenient way to keep bias and prejudice and, frankly, eugenic thought in action against people with disabilities out of the conversation.

Faye Ginsburg: In 1990, we got invited to write an *Annual Review of Anthropology* chapter on the politics of reproduction. In any case, we wanted to do this together. And it was a fantastic experience. I don't remember exactly how, but we proposed a conference to expand this topic. It was just taking off and anthropology had so much to contribute, and we wanted it to be much more international.

Rayna Rapp: 1992 was the conference. 1995 is *Conceiving the new world order*[5] that came from that conference.

---

[5] Ginsburg and Rapp (1995).

Faye Ginsburg: Many years later, in 2004,we received an award at the American Anthropological Association (AAA) meetings for that book from the Council on Anthropology and Reproduction. I think that made it clear that reproduction had emerged as a substantial topic. And we are certainly not alone. To us, the expansion of reproduction into these questions around disability came, I would say most strongly from the research that Rayna was doing. And then, of course, my experience with my daughter, because I got thrown into the middle of all these questions. It took a while to get her diagnosed and I had no experience. It raised all these questions that were so existential, about why these domains of knowledge are so separated? How do we make this conversation about reproduction and disability come together without, as Rayna was saying, judging people for making the kind of decision that Rayna made? Do you want to talk about that, Rayna?

Rayna Rapp: I got into the genetic testing and disability connection the hard way as a then 34, almost 35-year-old person. I was sent for an amniocentesis without even thinking about it, and then came back with what is so antiseptically called a positive diagnosis of Down Syndrome and my partner and I decided to end the pregnancy. It was very confusing and very isolating. I felt like the only person at the end of the earth that ever had to try to figure this out and I started using my medical and feminist networks to talk to other women who had gone through getting a "positive diagnosis". This is so long ago, the year would have been 1982, 1983. Talking to women, you still had to use a regular dial-up telephone and a phone book rather than all the cell phones we now use. But I talked to women all over the country who had this experience. There were very few of them. Nobody had ever talked to anybody else. And I started writing about it. I wrote about it in *Ms.* magazine, most notably because I wanted it to be a popular feminist article and not a medical discussion. One that feminists themselves took on as ethical consideration. That was a piece of it. I started to do research on prenatal testing and every place I went, the medical world opened its doors. They were like "yes, we don't have any idea what the impact is of what we're doing. If you want to go talk to people if you want to interview people if you want to follow our genetic counselors if you want to hang out in the labs if you want to go talk to families who did or didn't choose to use this test. Yes, yes. Yes." So that became the work that I did.

Faye Ginsburg: Just demonstrating the feminist principle of the personal is political.

Helena Fietz: I was thinking about the debate on Zika virus, pregnancy, and abortion in Brazil recently. Since abortion is illegal and very stigmatized, there was a lot of discussion if women who were diagnosed with Zika virus should be allowed to have an abortion or not. Those were often presented as an opposition between disability rights and women's rights. Of course, with several scholars like Anahi Guedes de Mello and Debora Diniz arguing against this opposition. Building this bridge between disability rights and reproductive rights, as you have been doing for so many years.

Rayna Rapp: And I would just add one thing to what you just said, Helena, that the technology itself continues to evolve at what I would call a frightening pace. Because unlike 40 years ago, technology is overwhelmingly in the commercial sector now and there is a different set of pressures to use it. The technology itself reveals things that people don't necessarily know how to interpret or can only interpret partially and it adds to the pressure on women. On the one hand, that technology is much easier, new blood tests, etc. On the other hand, the pressure to assume the normalization of this knowledge is just ongoing, and it's fierce. Again, I'm not arguing don't do it, but I just got off the phone within the last 72 hours with somebody who herself has a genetic condition and is now facing this in IVF because you can test an embryo and you can decide about which embryo to implant if you decide to go with IVF. Which of course itself is a very commercial, very expensive technology. This question is not going anyplace in the near future. The assumption that technology will solve problems. Again, this is like dialectics 101. The technology solves some problems while opening up new problems. That's something we would probably say about every technology and that is certainly true in the realm of medicine. If you look at anything about genetic testing, or reproductive technology, or the way in which all of these technologies circulate in the global economy, it's very selective. In Brazil, from what I know, upper-middle-class women have very different access to reproductive technologies than women from the popular classes. That means everything from the knowledge about it, to the services for it, to what you do if you get information. That is very problematic. It's highly stratifying all the time, even while it's expanding like crazy. It has always happened here before *Roe vs. Wade* and it will continue as our Supreme Court undermines legal abortion. I want to be very clear that this is not straight shot evolution, in which the rich countries have the answers.

Helena Fietz: The moral implications of deciding, as you have extensively written about, to terminate the pregnancy fall on women, and then the moral and practical implications of caring for the person who may need more care also ends up falling to women. In that sense, it connects your work on disability to reproductive rights, reproductive justice, and feminism.

Rayna Rapp: That is the foundation on which we are always building, and I would also say that it continues to escalate. It's different in different decades or generations, but the intersectionality of disability with not only gender but racial, ethnic, religious, class, and language-based differences is ongoing. And again, none of those things are going away, they get reproduced; it has a different meaning right now, but the meaning of, the word in IVF is "egg donation". Those are quote marks I'm putting up with my fingers. It's not a donation, it's a sale. And women who sell their eggs tend to be from other backgrounds than women who purchase eggs. Those are ongoing dilemmas.

Faye Ginsburg: Just as a reminder, I think one of the main reasons that people liked *Conceiving the new world order* is because of the idea borrowing a concept from one of your former students, Rayna, Shellee Colen: *stratified reproduction*. You were just describing yet another iteration of it. It was such an important concept to introduce because the minute you say it, it's a paradigm shift. People say "oh yes, we see that going on there and everywhere." So whatever current form it takes we are aware of that stratification process that comes out of the commodification of reproduction.

Rayna Rapp: I want to just highlight what Faye just said with a shout-out to Shelle. She's still kind of astonished that people are citing articles she wrote in the 1990s. But that is a really important impactful concept, the stratification of reproduction which came out of her work with Jamaican and West Indian Anglophone nannies. Women who were domestic workers taking care of the children of New York City. They got hired by upper-middle-class families where instead of the man and the woman splitting the work, they paid another woman from a different national and ethnic and racial background as an immigrant to come and take care of their children. So that concept travels and translates in so many ways.

Helena Fietz: Absolutely. Forwarding to a few years later, we see that on your 2001 paper “Enabling disability: rewriting kinship, reimagining citizenship,”[6] you speak of an increase in genetic testing and reproductive technologies that work to produce “perfect babies” and, on the other hand, the rise of technologies that allow for the inclusion of people with disabilities and the growing force of disability social movements. A situation that you named the *doubled telos of modernity*. Twenty years later, this “doubled telos of modernity” seems more present than ever. Could you talk a bit more about this idea and how it has evolved over the years?

Faye Ginsburg: Those are very long-standing cultural threads in a way. That tension I don’t think is unique to the US. I think there are versions of it everywhere. But this fantasy of perfectibility and scientific control as opposed to the democratizing impulse of inclusion and the exponential increase in disability rights and the presence of disability publics and all of that. We’ve never quite talked about it this way, but I feel like that presence is so much more part of the public discourse than it was when we first wrote about it based on our own experiences and an emerging kind literature. And now there’s a lot.

Rayna Rapp: Well, in fact, when we started talking about disability, which led to the 2001 article you’re indexing, Helena, we thought okay, this is a social landscape. There’s a map that we need to make because everybody got a diagnosis for their own kid. My second child has dyslexia, and he was diagnosed in relation to schools and special education. Faye described to you the situation with Samantha. We all experienced that as individuals. And Faye and I looked at each other and said: “No, wait, something’s changing. The law has changed,

---

[6] Rapp and Ginsburg (2001).

deinstitutionalization has changed, civil rights have changed." But we set out to map a landscape that we didn't really know existed. And later, by the time we started the book, having published umpteen articles, we were able to say: look, something changed and the 1990 passage of the Americans with Disabilities Act (ADA) is a landmark moment from which you can start to plot some of these things. Some of them start much earlier. Deinstitutionalization starts in the 1970s and 80s and forward. But without the advocacy and the activism that led to the Americans with Disabilities Act in 1990, the things we were trying to map would not be as present as they are, maybe they wouldn't be present at all. And that became the anchor point for the book and for many of our talks and subsequent articles: understanding the hidden history that has been revealed mostly by disabled scholar/activists themselves and their allies. And there is more to come. I don't know if people in Brazil have seen *Crip camp*? We went to the January 2020 opening at the MoMA Documentary Fortnight and it was astonishing and wonderful. It's about the hidden history of the enforcement of 504, which is the Rehabilitation Act. In this country, that precedes the Americans with Disability Act and we looked at each other and said: why don't we know this history? We've been on it for 20 years at that point and we still didn't understand what 504 meant until we saw that film. There is so much history to still be told.

Faye Ginsburg: I want to say one other thing in addition to the history revealed by *Crip camp*. When my daughter was born, I think one of the first moments of self-reflection was: how come I don't know anything about disability? This experience is so widespread; it's 24% of the U.S. population. Where wer these people when I was growing up? How come I didn't know? And then, of course, you realize, well, because they weren't allowed to go to school. I went home and asked my parents, I said: "Where were the kids with disabilities?" I remember there was a family we used to celebrate holidays with who had a Down Syndrome kid who had been sent away. That was what many people did then. My parents would literally walk me up and down the block I lived on in Chicago, and say this kid was at home, they had no place to go. Either they were sent away or they were probably locked up at home. That's the kind of difference in our experience from what we have been teaching. Our classes are filled with post-ADA students who themselves had schooling and were able to go to college. Before they couldn't. They couldn't even make it through high school before because it just wasn't available. And now they are in our classrooms, and they come in with such completely different views of disability. Some of that was just reflecting on our own history and how much had been rendered secret and the cultural energy went into repressing the reality of disability and the labor of caregivers, women primarily. I think when we wrote that 2001 paper, we were teaching ourselves about what happened. Why had disability been hidden and was finally coming out? Also, there was this emergent first-person literature about disability; previously, those stories were rarely told. Rayna could talk about it.

Rayna Rapp: I only add as a footnote to what Faye just said that after I published my article about the politics of genetic testing as a feminist issue in *Ms.* magazine, I was contacted by a mother of a child with Down who was herself an activist, and she said "well, you write about this, but you're not right about that." And I said, can I learn from you? Can I come to your support group? She said sure. So I spent a bunch of years going to meetings of parents with kids with Down and working on their educational policy committee, helping document the first classroom which was in a Catholic parochial school, I watched as the parents of kids with Down Syndrome just battered down the doors of educational institutions, because if those kids were entitled to anything, they were entitled to something called MIS, which is basically life skill training. How to count change or how to take a subway, but nobody was giving them any education. That would have been in the late 1980s, so it's ongoing. Now you've got kids, some with Down, who are in college-based programs. But that's post-2008, 2010, when the law changes again, so it's an ongoing set of contradictions, tensions, conundrums, and the democratic inclusion movements for that. Legislation for that. Mandates for that. It keeps growing at the same time that ideologies about perfectibility through technology and the claims of medicine keep growing.

Helena Fietz: In Brazil, it is not so different. Our Statute for People with Disabilities is from 2015 and, of course, the UN Convention on the Rights of Persons with Disabilities, from 2006, had a big impact in Brazil as well, but that is a lot in the history of disability and about the social movement of people with disabilities that are still unknown from public debates. Even though a lot has been achieved in the past years, here also, with more public debates and perhaps more rights and policies, it is an ongoing process with a lot of pushbacks. Particularly in this context in Brazil, there have been so many setbacks and there is always a fear that there will be more.

Rayna Rapp: Always. So, another anecdote. I've just worked with a group of disabled artists, mostly with intellectual disabilities, who produced a film, a different group of them do poetry and another group does theater. But in any case, the way that the woman who convenes the group, who is a genius of a mentor, describes what's going on, how she talks about all the diversity is that you are all artists who live under Medicaid regulation. You're living under those statutes. And she's not going to say you have an intellectual disability, she's going to let them describe their own neurodivergence but she is saying what you have in common is you are all disciplined by governmental medical regulations by which you get whatever resources you are entitled to. And believe me, they are never enough. But it also means that you then have to jump through all the hoops and do everything to make them believe that you are following the regulations, or you are at risk of losing your benefits.

Faye Ginsburg: It's bad when they're in school and they have very clear entitlements that have to be enacted very quickly because (for example) you're only 10 years old once. But the kinds of things you need once they're out of school are not so easy to attain. A lot of people refer to this as the "disability cliff".

Rayna Rapp: Right. Falling off the cliff. When you lose your benefits because you aged out of public education, where for all its bureaucracy, and with services that are often not very good, your rights are very clear cut and they've been litigated for years and years and years. Whereas the newer forms of disability benefits for people who have left school are much more opaque.

Faye Ginsburg: It's very, very time consuming. I am months behind on my daughter's paperwork. It's a whole job. There is a book called *On your own without a net*, a title that completely captures how difficult it is. Bureaucracies are intended to make it difficult for sure. I have to tell you a funny story and I don't think we have any of this in the book. When Sam was little there was an organization called Project DOCC started by three activist mothers of disabled children who were very tired of doctors not understanding how to talk to the child and their family and how to understand the pressures they're under, and so forth. I went through their training, and I became a volunteer for a couple of years to work with medical students, because they're very young, some may have experience with disability, some zero. The volunteers do grand rounds once a year for medical students to hear the experience of families with infants and very young children with disabilities. Then you're supposed to have a home interview where you invite the students into your home with another parent with you so that you can tell different versions of the same story. It's very interesting, very choreographed. You have these very young doctors sitting in your living room with their mouths open and their eyes wide and the organization tells you: don't clean up the part of your apartment where you do your insurance and your bureaucratic work. Because we know it's a big mess and you're going to feel like you have guests coming to your house. Do not clean it up! Tell them what that is like! Tell them how much work there is! When they first did that I was like what?? And then I got it: oh that is completely right. It's just the kind of material expression of that. In our book, we call this *moxie moms*. Because they're mostly mothers. Rayna and I have this fight: I say, parents and she says, no, Faye, mothers.

Rayna Rapp: I want to go on record saluting Faye's husband, Fred, who has always been a very active father to Sam. But mostly, as you said, the burden falls on mothers both representationally and practically.

Faye Ginsburg: We were trying to come up with a word that describes these women. They were not born social activists. They became social activists out of desperation, and the frustration of bureaucracy, and the people who stood in the way and who were discriminating against their children. *Moxie* is a word that has a really interesting older derivation. It means having a lot of nerve and courage. I think of it as a term used in 1930s detective movies describing the girlfriend of the gangster.

Rayna Rapp: These fierce advocates for their kids will do anything and punch you in the jaw if they can't get what they need for their child. That's a *moxie* *mom*. We have a whole vocabulary that we don't know how much other people like. Whether it runs from *doubled telos of modernity* or borrowing Shelle's *stratified reproduction*, but it certainly includes *moxie moms*.

Faye Ginsburg: Just to throw out a couple of the phrases that we have been very helpful for us.

Rayna Rapp: *New kinship imaginaries.*

Faye Ginsburg: Well, the *rewriting of kinship*. That people have to reimagine those relations and the temporality of them, and the unanticipated responsibilities. We've been circling around this question. There are a lot of people with very difficult conditions, like my daughter. We didn't have adults with FD; when she was born, her life expectancy was 10. Now she has adult peers. I mean, it's a small community, it's very rare. Then we also have people living into adulthood with autism and Down Syndrome. Many people, because they lived at home and grew up post ADA, got educated. They had proper care. Sometimes the care issues with Familial Dysautonomia are so complex, but with simple technologies such as feeding tubes, people survived without getting so many pneumonias that they couldn't make it past 10. This is part of it. Just the temporality of that and we're seeing in these parents' groups that I'm part of online. They are grappling with what the anthropologist Pam Block calls *unplanned survival* of their children into adulthood. Some are expressing the taboo sentiment that they don't want their adult disabled child to live beyond me. Because they don't believe that anyone can care for them the way they. Also, partially because once the terrible era of institutionalization collapsed, as it should have, there has not really been a social solution to that really big issue of support for ageing adults with significant disabilities. This was an unanticipated kind of demographic shift resulting from improved medical care and education and all those things that have led to this new kind of kinship dilemma for a lot of people. Rewriting kinship around different temporalities looks different over the life cycle.

Helena Fietz: An important aspect of that, as you said, is hearing from mothers of adult children talk about how they worry about dying before their children do like I did in the early stages of my research. Something that challenges our assumptions about mothers of adult children.

Rayna Rapp: The first time I heard that it was coming from a mother. She was a Spanish speaking mom on the Lower East Side of New York. I was in her home with her 20 year-old son with Down Syndrome and she said: “I only hope that he dies before I do.” When I repeated that to genetic counselors as a lesson, they took it to be about her and fatalism. I was enraged because I understood she was talking about the lack of institutional support. She was saying, nobody will take care of him, not only because nobody will love him the way I do, but nobody will be sure that he is washed, dressed, healthy, surveilled, all the things because at that point, that early, not that many people were living with Down Syndrome to his age, and now that age has doubled. That’s a dramatic difference in unplanned survival that’s going on with so many disabilities. And the fact that each one gets rediscovered as an individual, psychological problem, rather than an institutional problem of providing humane and respectful care to families, as well as to the individual with a disability is the ongoing struggle.

Faye Ginsburg: But that’s so interesting how that jumped out at you so early in this project, Helena, because it’s huge and it’s interesting. There’s really not very much written on it. I’m on parents’ group lists, email lists, and people say things like: “I would only say this to this group.” I mean, there’s such as social taboo to say something like that in public, not with a sympathetic anthropologist listening to you or a group of parents who completely get it or Rayna, but it’s big. And it feels like it’s erupting now because I think some of it is that the kids could live or live well at home, could get educated. I mean, there are just so many features of this.

Helena Fietz: I want to talk a little more about this idea of *rewriting kinship*. One of the things that draws my attention is how these ideas call us to focus on the domestic aspects of disability.

Rayna Rapp: Well, it entails everything from learning to put a kid in an early intervention nursery school that you didn’t anticipate and have to find out about to maybe ramping your house or working with whoever owns your building to get a ramp at the front door if it's not there. It might entail things like we've been talking about, such as the paperwork for the benefits to which your child is entitled because getting them the services they need will be costly. It's very concrete, nuts and bolts. But it's also much more. A moral or an ethical or even a communitarian kind of orientation that says, I love this person, I value this person, I honor this person, and this person is entitled to a good a life as much as anybody else and whatever that will take entails such an enormous amount of work. I will go on what seems like a tangent, but I promise you it isn't, I hope it isn't. There is a very wonderful genetic counselor who's a research counselor named Barbara Beisecker. She talked about working with a Down syndrome parent support group at the University of Michigan hospital, which is where she is or was then located, and how the parents group just knocked her socks off. They were so amazing. They were people who all said, I had no idea I had this was in me, but I am now a fierce advocate for my child, I will change the schools, I will change my church or temple, I will change the local playground, I will change anything that gets between my child and the opportunity of having an absolutely acceptable and good life. She was so impressed with these parents that when people would get a prenatal diagnosis of Down in their pregnancy, she would invite members of the parents' group to come to talk with them. She thought that would give people the courage to maybe consider whether they would not have an abortion. But in fact, it had the opposite effect. Everybody, she introduced those families to went on to an abortion to end the pregnancy and what they said was: "I could never be as strong or as amazingly activated as those parents are." Of course, Barb was horrified by that. Because what the message is, is that you have no idea that you will have to do this and you have no idea that you can rise to this occasion. None of us imagine the challenges in our lives in general until we have them and this is one you cannot imagine, but when it happens, the vast majority of you will rise to the occasion and do the right thing for your kid. And that's what family life is about. So kinship, rewriting kinship, imaginary, whatever you call that, it is a developmental process. And it's a family journey, or it's a life narrative. Use whatever chronology or sort of arc of transformation you will, but it's not something you can really imagine until it happens. On the other hand, having the kind of resources out there that Faye was talking about, having parents' groups, having places to go now on the internet so you can get the information is an enormous advance in trying to break the isolation and feeling like you've just landed on the moon and you don't know what you're supposed to do to take care of this new baby.

Faye Ginsburg: The other piece is just realizing how kinship stories are built around expected temporalities. Marking events. I think the most important lesson you learn early is: throw away the book with all the milestones, because it won't help you and will only depress you. You are going to be on your own schedule, on your own temporality. Rayna has observed this in her book. The really hard times are when you go to a family reunion and everyone's talking about their kids' Bar Mitzvah, or their graduations or whatever, and you're just on a really different temporality and your outcomes are not known. As I said to some of our younger colleagues who invited us to baby showers, and inevitably the ritual is that you go around the room, and you tell your story about having your baby, and I always say don't ask me. They might say: Oh, please, please! And you say, Okay, I told you. And then everyone's just very quiet. It's a terrible moment. The routinization of kinship means that you have to invent a different imaginary for which you make joy, how you manage all the household routines. My husband and I are still getting up in the middle of the night, having to fix medical equipment or give medications. I can imagine people don't want to be told: yes, your child will still be with you at age 32 and you'll be getting up in the night, like when they were an infant. You don't want to hear that part. It's also very hard to be able to explain to people the kind of existential joy that you have, just the recognition and joy, that's very different. I will say social media has made a huge difference.

Rayna Rapp: That is an understatement.

Faye Ginsburg: It's very interesting. That's where you hear a huge amount of support. Because you also curate the social world that is responding to you. It's interesting because you don't live in the same kind of face-to-face communities necessarily. You do live in those, but that's not the only place where you're able to gather a kind of social world around you and that has been really important. One of the things we've been writing about is disability publics in the arts, how the first move was to devise all these ways to accommodate those who are blind, deaf, autistic, or have dementia. There are many different creative ways of making cultural spaces available to people. One of the things is something called social narratives, which are kind of storyboards with photographs and little comments on the bottom, meant especially for people with anxiety disorders or autism. They say things such as: "when you come to the Museum, you're going to have to cross a very busy street and here's what it looks like. When you get there, a guard will want to look in your bag. He is there to make sure everyone is safe." These are things that most people take for granted.

Rayna Rapp: Well, not being able to imagine the full trajectory of a visit to an museum is really what it's about.

Helena Fietz: This takes me to another question which is this underlying tension between parents' groups and self-advocacy groups, which are more and more common in Brazil for autism, Down Syndrome, or intellectual and developmental. Do you find that tension in your work?

Faye Ginsburg: That tension is also historical.

Rayna Rapp: In the 1930s and 40s those parents who resist institutionalization are very isolated, very alone, very stigmatized. Some of them are families of great means and resources and some families start to get together and talk about what it will take for our kids to thrive and survive, and not put them in an institution, not hide them away. That movement, the parents' movement, is kind of the hidden history for a long time. After deinstitutionalization, in the 1970s into the 80s, which at least in this country is an important moment, some people are returned to their communities and some people grow up with disabilities in their families, schools, houses of worship and they start to take the lead in the disability rights movement. There's an extreme kind of antagonism that happens between some parents and some children in some of the autism organizations in the late 90s, early aughts, because the parents are still speaking for young adults who want to speak for themselves. They feel like whether it's right or wrong, the stereotype is that parents want to cure and they, the people with autism, want services and acceptance for who they are, not some way to fix or change them. So that's one set of tensions. But there are plenty of places where people with disabilities become leaders and for many parents that's a great relief to see their kid have a meaningful life in which they are effective advocates for themselves and for others, and they can admire their work with their kids and the organizations that maybe they started in at one point, have morphed into something much more appropriate to the present moment.

Faye Ginsburg: In our research, it's not like there's tension. My daughter did public speaking since the age of 10 and now she's saying she does not want to. We have a big international Dysautonomia Day, she doesn't always want to go. She's really sick of talking about it. It changes over the life cycle. One of the things I remember when we were looking at these early parents' groups; they would take out an ad in the newspaper to find other people. Or like with Bernie Rimland, with autism, people would tear out the back page in his autism book and send a little note to him. It is fascinating when you realize how much we take for granted and what has been facilitated by social media. But the impulses were similar. Of course, it was to try and locate other likeminded people who were saying: "we've got to change this."

Rayna Rapp: But then again, the unplanned survival. More and more people are living into adulthood, and then into middle age and some into old age, with disabilities. Again, if you go back to the 1970s, and 1980s, the expected lifespan of a person with Down was somewhere between 10 and 15. Now, people are living into their 40s and 50s, very commonly. So as all of those trajectories change, the possibilities for self-representation are very different now than they were in that period that Faye was describing to you, the 1940s and 50s, when those kids weren't likely to survive without their parents becoming their fierce advocates. And that's a very different moment than this one. We wrote that anthropology was late to the table. Rosemary Garland-Thompson, who is one of the luminaries of disability intellectu, wrote an article in 2013 called "Disability studies: a field emerged." That is, it's not an emergent field, it's here and that's really important. It has a history and a legacy that reflects the move from disability rights at the individual level to Disability Justice at the social level. But anthropology has been very late to the table. And we can ask a lot of questions about why. We are thrilled that the Wenner-Gren foundation, once again, supported our work and an international conference at an accessible site.

Faye Ginsburg: When we wrote that review essay, "Disability worlds",[7] in the *Annual Review of Anthropology*, that was our agenda: to resurrect the literature. There were these important early works, but it took a while until people thought of disability as a significant topic for anthropology. Even though, as we argue in that piece, disability is the most fundamental form of human difference on the planet that is shared everywhere. One of our theories have been that a lot of people are attracted to anthropology because it seems like you must be very intrepid and adventurous, so it's kind of ableist in a lot of ways whether it's in Brazil or the US or wherever it's located. We had an agenda for about five years, to show people at the AAA meetings that disability is an incredibly intellectually exciting issue to think about. So many key topics that are central to anthropology like kinship, life cycle, temporality, stratification, so many things that need to be addressed. I don't know if we're chipping away at it.

Helena Fietz: In Brazil, the first open panel on disability at our biannual Anthropology Conference (RBA) happened in 2014, organized by Adriana Dias, who is a disabled scholar, and since then she and other folks like Anahí Guedes de Mello, also an anthropologist and a disabled women, have been pioneering this field of an Anthropology of Disability in Brazil, and gathering more and more anthropologists from different departments to join, forming committees to push further accessibility in Universities and events.

Faye Ginsburg: We see this with each generation. People have grown up with a far more disability-rich atmosphere. People are experiencing it and understanding its value.

Helena Fietz: So as mothers of children with disabilities, I know that you have also been engaged in disability activism throughout these years. I was wondering how your experience as activists impacts your research and, on the other hand, how your academic worked has impacted your activist and, why not, mothering practices?

---

[7] Ginsburg and Rapp (2013).

Rayna Rapp: That's the way we've been talking about it throughout.

Faye Ginsburg: I think I was an activist before I became a scholar. Like in a lot of feminist research, it's hard to disentangle the scholarship from the other forms of knowledge and certainly, activists and advocacy are part of that. There are so many insights that I would never have had if I weren't a mother. Rayna became very active with this amazing group called Eye to Eye because of Teo, which is organized people with dyslexia and other learning disabilities. I had my great eureka moment about transition from entitlements to education to adulthood. Because I was running around trying to figure out where do I find this transition for my daughter? I found this report called *Transitioning to nowhere* put out by an advocacy group. Do you remember this Rayna? I walked down the hall to your office and said "I'm not crazy! There isn't anything here."

Rayna Rapp: And I will say something else, which is we were both interested in social activism and social action long before reproduction and disability. Certainly, Faye is describing is a certain time and activism has changed since then. But I was part of that generation that made women's studies and that was a very utopian project. We thought we were going to have solidarity and sisterhood with all the kitchen attendants at our universities, right? As if, right? But women's studies became gender studies, then it became sexuality and gender studies, then it became LBGTQ studies, it became intersectionality studies, and so on. That's decades of work on the part of many activists. I think we both kind of grew up with that sense and also a sense that it's okay not to know. That is part of what Faye's talking about: being an advocate or an activist before and while you're an academic. You freely admit that you only understand part of the world and need to understand other things if you want to intervene and make effective change. And that is a very different orientation. In the old days, and I'm talking a bunch of years before Faye, but in those older days, the assumption was that academia was different. And that while maybe you might have a critique of objectivity or objectivism it wasn't the same thing as letting those questions about active intervention and change into your research. Those things evolved in our individual lives, and they continue to evolve in the lives of our students, and it's never easy. And whatever they're facing is somewhat different than what we faced.

Faye Ginsburg: I will say, I think where these things come together was creating something at the university. One of the things we have been able to do is build the Center for Disability Studies at NYU. It has allowed us to develop a presence in the city with disability activists. It has been great for us to be able to use our academic location to showcase the work of activists, artists, and disability scholars. Being able to build something like that is another kind of activism. That's a kind of privilege: we have been able to use the university to build this work in collaboration with people around us. In fact, one of the things we are hoping to do is develop an archival project documenting the lives of the people who were foundational activists in the Disability Rights Movement and Disability Arts Movement. Many are now in their 70s, and they live in New York. They will want to give us their papers, and we want to do interviews with them, and start developing an archive with them for future scholars. This has been an interesting and unexpected way in which we've engaged with breaking down barriers between the university and the city and the disability movement around us.

Helena Fietz: To wrap it up, going back to the book you are writing now, over thirty years after the beginning of your partnership, I was wondering if you think your life course as mothers, activists, and scholars have affected how you think about this book.

Faye Ginsburg: The simple answer here is yes. We kick ourselves saying "Oh, we should have written this book 10 years ago, but it's a very different book because of what we've learned about things like unplanned survival as well as disability arts.

Rayna Rapp: Newer political mobilization organizations explicitly by and for people with disabilities have emerged. It's all part of the landscape that we were trying to map 20 years ago; it has exploded into so much more complexity. And that's fabulous and very inspiring, but also at times overwhelming for us to get a hold of. There is so much going on. And the book tries to catch up with all of that.

Faye Ginsburg: I would also say that our positionality is complicated; we are abled-bodied, but intensely related by kinship to disabled adult children. We haven't had this conversation, particularly. We've organized a lot of things, we've invited so many people, we've built a Center for Disability Studies, we've supported students, we've helped make a foundation aware of the need to give funding for this. We're not perfect by a longshot, but I think people are respectful of the fact that we've put our shoulders to the wheel to make things happen for disabled people.

Rayna Rapp: Of course, as you said, that's the privilege of living in a university; you have some resources. So, we have been able to make a lot of different things happen at different moments.

Faye Ginsburg: Other issues have come up during the pandemic. For example, as we moved so many activities to Zoom, many people are calling us and asking us for accessibility help. One of the people who works with us, activist-scholar Kevin Gotkin, calls it being an access doula. I just love that phrase; that's exactly right. I am not sure if Kevin came up with this phrase or if he got it somewhere else, but it's interesting. How do you give birth to a disability-friendly world?

Helena Fietz: I want to thank you so much. It's very good to see you again, and be able to talk to you. When I first read your work I thought: "Oh, no, they were doing this 20 years ago, maybe I should try something else." But then I thought: "Ok, there is still room to talk about it. More things to unpack here." And this interview just made it even more clear how this is, as you said, and "emerged field", but how we can always keep adding to it.

Rayna Rapp: There's so much room, and it's so encouraging to us to feel that we're part of an international movement interested in the politics and intersections of reproduction and disability. So, thank you for your interest.

References

GINSBURG, F. *Contested lives*: the abortion debate in an American community. 2nd ed. Berkeley: University of California Press, 1998.

GINSBURG, F.; RAPP, R. The politics of reproduction. *Annual Review of Anthropology*, [*s. l.*], v. 20, p. 311-343, 1991.

GINSBURG, F.; RAPP, R. (ed.). *Conceiving the new world order*: the global politics of reproduction. Berkeley: University of California Press, 1995.

GINSBURG, F.; RAPP, R. Disability worlds. *Annual Review of Anthropology*, [*s. l.*], v. 42, p. 53-68, 2013.

GINSBURG, F.; RAPP, R. Disability/anthropology: rethinking the parameters of the human. *Current Anthropology*, v. 61, suppl. 21, p. S4-S15, 2020.

RAPP, R. *Testing women, testing the fetus*: the social impact of amniocentesis in America. New York: Routledge, 1999.

RAPP, R.; GINSBURG, F. Enabling disability: rewriting kinship, reimagining citizenship. *Public Culture*, [*s. l.*], v. 13, n. 3, p. 533-556, Fall 2001.

Recebido: 29/04/2022 Aceito: 30/05/2022 | Received: 4/29/2022 Accepted: 5/30/2022