

Disability History Association Podcast
Interview with Sandra (Sandy) M. Sufian
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Kelsey Henry: Hello, and welcome to another episode of the Disability History Association podcast. I'm Kelsey Henry.

Emma Wathen: And I'm Emma Wathen.

Kelsey Henry: And it's our pleasure today to be in conversation with Professor Sandy Sufian. Sandy is a professor of Health Humanities and History in the Department of Medical Education at University of Illinois Chicago and a professor of Disability Studies in UIC's Department of Disability and Human Development. Sandy, thank you so much for being here with us today.

Sandy Sufian: Thanks for inviting me. It's gonna be fun.

Emma Wathen: Definitely. So, can you start by telling us about your path to disability studies and disability history? Did you come into academia with the expectation that you would be researching and teaching in disability studies and disability history, or has your positioning within the field surprised you?

Sandy Sufian: I did not come into academia—well, I did come into my first position, my only position at UIC, doing disability history. But when I got my graduate degree, I was doing Middle East history. So, I decided to do my dissertation on the history of infectious disease in mandatory colonial Palestine and through that I started to think about disability and land. I had a postdoc in Oregon and that was when the NEH Institute on Disability Studies at San Francisco State University was held, so I applied and got in, even though my background in disability studies at that point was pretty minimal. But it was a transformative experience for me. I think I was the only person who worked on a non-western even non-American context. But I got to meet some major and fabulous disability historians: Paul Longmore, Catherine Kudlick, and so that was a transformative experience for me. We read, I don't know, like 100 pages or 150 pages a day. So, it was a lot. It was a dive into disability study, and it was just fabulous. I came out of that knowing that I wanted to do more disability history and used a lot of what I learned to inform the revisions of my dissertation for a book, even though I think that the book itself is probably more centrally situated, that first book, in the history of medicine, particularly history of colonial medicine. And then once I finished that book and started thinking about my next projects. I moved more centrally into disability history. By that point, I was already teaching disability history to medical students from 2002 to probably 2008. So, I had been teaching it and really getting to know the literature and the scholarship in the field. By the time I decided like, okay, it's time to write my disability history book. I knew people, I was going to SDS, and I was involved in the field, but I hadn't like written a central disability history monograph. I had written some articles already. That's how I came into it. So, this adoption book is the first book I've written on disability history as the main thing.

Kelsey Henry: We get a lot of historians of medicine on the podcast, and I know Emma and I both are trained at least, in part, as historians of medicine. It's a fairly, as far as disability history goes, a fairly common or like well-traversed migratory path, even though that looks so different for each person. Let's hear a little bit more about your first big book-

length foray into disability history. Sandy's most recent book publication is titled *Familial Fitness, Disability Adoption and Family in Modern America*. It was published by University of Chicago Press in 2021. And we're really excited to talk with you about it today. You already mentioned when you were sharing with us your transit into disability history that you started with projects that were not situated in a US-American context. Your first two books were *Healing the Land and the Nation, Malaria and the Zionist Project in Mandatory Palestine*, and *Re-Approaching the Border, New Perspectives on the Study of Israel-Palestine*. You've said a little bit about what prompted this topical shift, or perhaps like a sub disciplinary shift towards disability history, but more specifically, how did you end up working on a project on disability and adoptive family building in 20th century America?

Sandy Sufian: Yeah, so the shift from the Middle East to America was a huge one for me. I mean, I had to learn American history by myself. So, it took a long time. You know, there's just the overwhelming vastness of the scholarship in American history compared to Middle East just took me for a loop, but the ease is that it is all in English, which is terrific. That was much easier for me. So, how did I get to adoptive family building and disability in the doctor family building disability and adopted family building? Actually, by way of considering issues around assisted reproductive technology and biological family building and disability. Some friends that I had at the time were really concerned about disability and their family building projects, and so I started to think about what it is like in an adoptive case where the child's already born and you're making decisions, very explicit decisions, about building a family in relation to disability. So that's pretty much how I came to it. It was sort of this convergence of conversations I was having with friends and then just thinking about how can I think about this in more concrete terms? An adopted family building really was a great way to do it.

Emma Wathen: Great, so let's dive into your book, starting from right before the introduction. So, you include this brief note on language that we'd like to touch on with you just to give our listeners a little more context for some of the language you are using to describe your historical actors. In your note, you introduced the term "children labeled disabled," a term that you use alongside disabled children and children with disabilities. So why did this feel like the most appropriate language to use in some instances?

Sandy Sufian: Yeah, so the children labeled disabled has to do with the attribution of disability without impairment in terms of adoptive practices and policies around adoptability. So, before World War II, children that had hereditary backgrounds and they themselves may not have had an impairment, but the mother—as it usually was—may have had mental illness or may have had some sort of impairment, physical, mental, emotional, and/or was sorted within this vast category of feeble mindedness. It really could be anything because that's like the garbage can category for a ton of stuff, including unmarried pregnancy, alcoholism, et cetera. The children born to these women and then placed for adoption are treated as though they have an impairment. In other words, they are excluded from adoption eligibility just like a child with an impairment would be, and so that attribution of disability risk for a successful or failed placement, usually the risk for failed placement, was considered very seriously, and so those children were not placed overall. I mean, there were independent adoptions that had nothing to do with agencies. We can't really trace them. So, it's very difficult to know what happened in that sense, but through agencies, they were overall excluded. Now, after the war, for a variety of reasons, which I get into in the second chapter of my book. There's a reconsideration of children labeled disabled. There's sort of this opening up post-war to consider those children with what we'll call pathological family histories or hereditary pathological hereditary backgrounds as eligible. Not children with impairments, but children labeled disabled. So, they're attributed that disability risk for this

worry about failed placement. And so that's why I use that language for those children. It's really to distinguish this group from children with diagnosed impairments.

Kelsey Henry: At many points in your book, you're describing the porosity of disability as a category, as a racialized category, through this concept. I think the language that you used in the book was, in the progressive era, pathological heredity. So, the idea of projected or anticipated risks of disability in children who did not have documented impairments, but because of their familial makeup, their background, were seen as being at risk for developing disability or having latent disability, or disabled attributes. I want to zero in on this concept of risk a little bit more because it's so central as a framework to the entirety of your book. Each chapter looks at what you call adoption professionals' calculus surrounding adoptive family building that usually revolved around changing understandings of risk, especially the risk of disability that impacted a child's eligibility for adoption. So, a very helpful phrase that you used in the introduction to describe this was the risk adoption disability triad, and that really can set up grounds for each of your chapters in different ways. You already said a little bit about what disability risk looks like in the progressive era, in terms of this concept of pathological heredity. I'm wondering if you can say a little bit more about how risk assessment and mitigations against placing children who were considered to be at risk for disability or already disabled among adoption professionals, how that risk assessment and that calculus changed over time.

Sandy Sufian: When I speak about the risk disability adoption triad, I'm playing off of what's considered in adoption, the adoption triad, which is the biological mother, the adoptive parents, and the child. So, it was a play off of that. What I'm saying is that there's this other triad that's happening at the same time. I mean the whole framing around risk comes from the discourse that I found in the archive in the documents so that I didn't really go in thinking that this was going to be framed around risk, but it's a pervasive discussion for the entirety of the 20th century and even now. It became clear to me that I wanted to think about it. But, in sociologies of risk—there's a whole literature on risk by sociologists—it very much sort of assumes a definition of risk and does not historicize risk at all, except for one wonderful sociologist named Deborah Lupton, whose work I love. She's a sociologist of health and medicine, and she makes this like small, maybe it's not so small, claim that we need to historicize this concept. And, so while I was reading all this stuff about risk, I took that and thought, this is a really important point, and nobody has done that, that I have read. There are some historical books about risk and financial markets, but in terms of medicine and health I had not seen anything that historicized this concept. It's just kind of taken as this thing that you know what it means.

So, I wanted to do that in this book, and that historicizing follows also the major substantive argument that I'm making in the book, which is the trajectory argument around the adoption of children with disabilities going from being excluded at the beginning of the century to partially included at the end of the century. That history of risk and disability risk as it relates to placement, adoptive placement, and whether or not an adoptive placement will fail or succeed, failure being that parents will return the child—there's a big fear of that throughout the whole 20th century, which would not be good for the child, agency, or anybody involved, frankly. There's a big worry about failed placement. The risk is related to that, and the way that disability is considered a central player in predicting failed placement.

The way that risk gets taken up at different periods of time, that I sort of look at throughout that trajectory argument, has to do with the idea that risk is sort of pre-war, risk is part of the child's makeup, like they are the risky ones. Then in the 60s, 70s, late 60s, there's an opening up, not only for adoptability of children with disabilities, meaning children with

impairments, but risk starts to get transformed or discussions around risk start to get transformed into that the child is not inherently risky, like they were seen before the war. Now, it's the social conditions that produce the risks for the child, and so that's sort of a liberalization of the idea of risk, but it follows and is consistent with adoption practices that become more liberal around considering children with disabilities. Then during the 80s with Reagan, particularly, and the moral maturity and just this total change to conservatism in the 80s, there's a reversion. In some respects, not completely but there is some reversion to thinking of children as damaged, children as risky. They are themselves risky, but they're also at risk. So, there's an idea of being at risk that happens in the 80s and into the 90s. There's these two things that are happening at the same time, and that again follows the foster care crisis and the welfare queen AIDS crisis discussions, right? AIDS crisis discussions and sort of the re-biologization of society and culture in America.

It also follows, to be honest, this more medicalized version of reproduction. What do I mean by that? There's IVF, right? There's abortion. These are two things actually that impact the way that adoption changes. Demographic changes are really important as well. Now, I mean, there's huge foster care needs, but single mothers start keeping their children or they don't have unwanted pregnancies, which puts adoption agencies sort of on the defensive, which is why they open up eligibility for parents. There's just a whole range of things that are happening all at the same time.

Emma Wathen: Thinking about disability and risk or the risk adoption disability triad is a conceptual framework that grounds the entire project. It comes up in every chapter. Now I'd like to zoom in on how this discourse around risk has transformed specifically between or during World War II and how adoption practices follow. So, we talked a little bit earlier about how fears of pathological heredity and eugenic sentiment excluded children labeled disabled from adoption, like from the progressive era through World War II. But then during World War II or right after World War II, you characterize this post-war period as one where adoption agencies expanded the criteria of child eligibility to be more inclusive. Can you say more, not only about the shifting ideological and conceptual factors, but also about some of the economic, demographic, and reproductive trends that prompted this broadening of adoptability in the post-war period?

Sandy Sufian: Sure, and also about risk, right? During the post-war period adoption professionals take on a discourse of what I call risk equivalence, which is that—now remember, it's still children with what is called pathological family histories, pathological heredity. These are the children that are being debated as to whether or not they should be included now and not excluded. Not children with impairments, that comes later. Not much later, but a bit later. So, in order to have parents become open to adopting children labeled disabled, children with pathological family histories, agencies start using this idea of like, well, adoptive parents or candidates need to be just as open as biological parents. Like biological parents don't get to choose what kind of child they have. They might have a child with, you know, with an actual impairment, and they don't choose, right? So adoptive parents can't be that picky. They need to start opening up their ideas to what kinds of children they can be matched with, and this has to do with like pre-war ideas around matching, whereby parent candidates would say, I want a girl ages two to four, she has to have blue eyes and blonde hair. Literally you can go to the archive and see these kinds of requests. And there's an idea that there has to be intellectual matching. So somehow, you give an IQ test to an infant, or a toddler, and you assess their IQ and you match them with whatever socioeconomic bracket the adoptive family or candidate family is from. There's a lot of strict matching that's based on what the kids look like and what you look like, because it was all a secret, you didn't want to reveal that you had an adoptive child, so you wanted

your child to look like you and have the capacity to have the same aspirations as you might intellectually or in terms of careers.

There's a lot of predictions that are happening here. Then post-war it's the baby boom, right? Because of the baby boom, and also economic prosperity in America, for the most part for white middle class families, there's suburbanization, etc., there's the beginning of way more candidate applicants to apply to be parents. There's a lot on that end, but not enough children that would fit the parameters of what's acceptable, right? That's when agencies start to say, you know, you can't be so picky, you're gonna have to accept the same risks as biological parents. So, it sort of follows with those demographic changes. I hope that makes sense. And that follows alongside changes in patterns around reproduction post-war.

Kelsey Henry: [00:27:19] That makes sense. I am so fascinated by this concept of risk equivalence, especially given what you were saying about when you first got into this project, at least in part, you were thinking about colleagues who were working on histories of assisted reproductive technologies, scholarship on reproductive technology and family building and these concepts of risk, and choice, and intention in family building that were made more accessible by advancements in reproductive technology. If at one point in the history of adoption and family building, you had adoption professionals really sending out a message that adoptive parents should be willing to assume the same risks as biological parents and that you never know what kind of child you're going to get. So, there's this sort of like liberalization of practices around family building and adoption in the post war era, at least somewhat, and then I wonder if like part of the story that you're gesturing at, with the advent of more advanced assisted reproductive technologies, that's the rise of more risk aversion, because now there's technology to facilitate the management and mitigation of risk. So, I just think this is such—

Sandy Sufian:—Of disability.

Kelsey Henry: Of disability, yeah. I have more familiarity with the history of assisted reproductive technologies and the history of adoption. Before I read your book, I didn't understand the connection between these two histories. But I see really when you think about risk, like it's very clear the continuity and the conversation between these two different kinds of family building.

Sandy Sufian: Absolutely. Actually, post-war too, in the history of reproduction, there's an increase in insemination. There's no risk mitigation there in the same way, but that is one of the beginnings of assisted reproduction, right? And then, in terms of sort of the present day mitigation of risk through pre-implantation genetic screening, gene editing, eventually, there's absolutely this intentional mitigation of risk. What's interesting in the assisted reproduction case is that because it's not regulated in the United States—which still just makes me shiver, I can't believe it's self-regulated through a physician association—a lot of the bioethical conversations turn to stating, let's look at adoption as the model for how to regulate assisted reproduction in the current day. Literally, they say, you should look to adoption to think about how to regulate this. It's kind of an ironic twist, right?

There's George Annis, he's an ethicist. He's at Northwestern, he used to be at Northwestern at least. He's a big guy who writes on assistive reproduction and he wrote a very important ethics kind of document. He explicitly says that we need to look at the history of adoption and look at the changes in the regulation around adoptive family building to help us think through these kinds of ethical issues. I mean, it would be great for somebody to do that kind of work, to put the two together. That's a huge project.

Emma Wathen: Really, this book opens that door, like wide open, which is really exciting for future scholarship and the projects that are going to build on your work.

Sandy Sufian: Hopefully. I mean, I was overwhelmed with what I had to do on this adoption book, so that it was considered in the background, but it wasn't my central, you know, but assisted reproduction, except for the 80s with the introduction of IVF, where I really needed to think more about it. But I think it's become even more interestingly tied together in the current situation. And also, the hierarchy, right? So that people try first to have biological children, then they really go to assisted reproduction, and then they almost like choose adoption as a last resort in many ways. Not everybody, but a lot of people. That was not a situation in the 50s. That just wasn't the situation. Really, I mean, through the 70s, because of the lack of technology and a variety of other reasons.

Kelsey Henry: Yeah, I mean, it's so fascinating to think about how advancements in reproductive technology reorganized the hierarchy or the way that you were describing it as the sort of plan A, plan B, plan C of family building that really maintained the primacy of biological kinship through technological means.

Sandy Sufian: Dorothy Roberts has written an article about the primacy of the genetic tie that's really important here, but also it is about disability risk. People will say, I want to do IVF because then I will know where the child is, like, I will have control over my body and what I put in my body and whatever. Or in surrogacy, the same thing. The adoptive mother per se is the one who can oversee and set some rules and parameters around the carrying mother, gestational mother. There's this idea of controlling the outcome that I think plays a huge role in the hierarchization of that.

Kelsey Henry: This is a little bit of a pivot, but I thought it could be helpful, like historically thinking about World War II, post-war moments, to talk a little bit more about who was in the room when it came to assessing children for disability risk and constructing adoptability as a quality that was measurable. You mentioned in the book that there were doctors, geneticists, psychologists, psychiatrists, who became more involved in adoption protocols and practices post-World War II. I'm curious about the professional networks of different kinds of experts who were weighing in on adoptability and disability risk? And did different kinds of adoption professionals assess risk differently or perhaps have different priorities when assessing either a child's fitness for adoption or a parent's fitness for becoming an adopted parent?

Sandy Sufian: That's a great question, and a difficult one, I think. So post-war, there is a proliferation around who is in the room as compared to pre-war. There are anthropologists that are asked to consult on mixed race children, and about their genetic background, this is in keeping with the development of anthropology as a discipline as well, but sort of what are the origins of these mixed race children and the physicians and psychologists I think have similar kinds of assessments of risk. They're drawing from child development studies, they're drawing from ideas around IQ being a little bit more fungible, starting with the slow consideration of environment and love, eventually, ideas around love.

There are studies by Harlow, for example, around monkeys and the absent mother, or the present mother and what counts as a mother. There's John Bowlby and maternal theories around maternal deprivation. These are huge, have huge influences upon adoption considerations around risk. So, case workers are deferring to these experts, right? This is also a huge expert kind of time, belief in experts, reliance upon experts, but there's also the professionalization of social work, I should say, that happens pre-war, but also post-war.

They themselves are gaining more legitimacy as a field, social workers, and they're interested in the home as a possible environment, maybe more so than physicians. So, I would say that there's slight differences, but I didn't sense that there were major differences, let's put it that way. And for agencies, they wanted to take into consideration all of those reports or ideas towards assessing who should be included or excluded, which children should be included or excluded.

Kelsey Henry: And that's a great segue to the next question that I wanted to ask you about, this trend of inclusion. So, you characterize the period from about 1955 to 1980 as years when adoption professionals, parents, and state and federal governments increasingly affirmed the adoptability of disabled children and strived to find families for them. So, what did this greater commitment to inclusion look like in practice at the level of addressing parental attitudes, the disability stigma, and also at the policy level?

Sandy Sufian: Right. This is a really important period of time. It's also a huge amount of time. But, so there is the consideration of children with impairments, children with disabilities to be included in adoption. And this means sort of thinking through how agencies were going to attract certain parents. So there is a slow opening process, not right away, of which applicants are going to consider. And at the same time, risk gets relocated outside of the bodies of children onto environmental influences. There are Sunday child, Wednesday's child, kinds of photo listings of children whereby children are intentionally talked about as whole people or not just their disability as a way to integrate ideas around humanity, that children with disabilities are humans and have a humanity to them. Therefore, parents should consider them. And then there's the sort of concrete, which is what you're talking about, in terms of policies. So, there's just a huge number of changes in casework practices and state and federal policies. There's the emergence of specialized agencies for what's called "special needs children." That includes the same groups, but they're called hard to place. This includes twins, siblings, older children, minority children, and children with disabilities, or what's called handicapped children. Those subcategories still exist, but they're recalled special needs, meaning special needs for placement, meaning that the agency that these children have needs for the agencies to facilitate their placement.

To be more specific, the agencies need to do training programs for caseworkers so that they are trying to work against disability stigma so that caseworkers will start to really seriously consider these children for placement. There's the permanency planning movement, which is a movement of mostly parents, some physicians and psychologists around the idea that having a permanent family is important for the well-being of children. This comes about because of what's called foster drift. There's the foster care crisis right in the 70s, which really becomes huge in the age of reporting of abuse and neglect in the 70s. And there are policies. There are subsidies right. So, there's maintenance and medical cost subsidies to incentivize parent applicants to accept children with disabilities in their home. I could go on and on and on, right? There's the incentivization, there's the ability for children—a little bit later than in 1980—on welfare to continue on welfare and Medicaid when they're adopted. Because the foster care system pays the foster care parents, but once the child is adopted, those parents would lose the child's Medicaid and any subsistence assistance. So, nobody could afford it. There's also, single women, single men, divorced people. These were all people that were excluded from adoption in terms of parenting. Then agencies start to liberalize their policies and start to accept these kinds of parents. So, there's a big opening in who can be eligible as a parent to adopt as well. It's a huge flourishing of massive cultural shifts and policies and practices that change to accommodate those shifts.

Kelsey Henry: I want to linger a little bit longer on this shift towards greater inclusivity when it came to who qualified as an adoptable child in the post-war period and how this

precipitated shifts in adoption policy and rhetoric regarding what constituted a viable adoptive family. This was so interesting to me, like the ways that race, class, and disability status of prospective adoptive parents shaped whether adoption professionals could see an organic match between a disabled child and an adoptive family, that perhaps a disabled child would be a better match or a natural fit with a disabled parent. But there were also anecdotes about matching disabled children with non-white parents, like the way that race and class was factoring into the way that matches were being made?

Sandy Sufian: So, the idea that disabled parents would be acceptable, that comes much later. That's like the 80s to 97. That isn't the 55 to 80 time. I found this fabulous letter from the Little People of America head, I think she was, saying we have people at our conference that are coming who are interested in adoption and please consider them...are there any children that have dwarfisms—what they used to call it—and so we have very qualified applicants who would be great matches. Now, I don't know what happened to that. I don't have any follow-up letter, but that was like in the 60s, so that's pretty early. To me, that was a surprise and an exciting surprise. Somebody who could do a more localized history might be able to find more examples of that, I think. But the idea that disabled parents would actually be ideal comes much later. There's also the background that I don't get into as much in this book because there's so much work on it already in adoption history on race and the place of race in adoption, right? But there are transracial adoptions in between 55 and 80, particularly in the late 60s is really when things take off right.

There are programs to facilitate transracial adoption, and that is because there are this growing population of children in foster care, who need families, need permanent families. And so, where are they gonna get these parents from, right? But they're also not considering families of color very seriously, and so the black social worker statement, that's a huge watershed moment in the history of adoption, whereby they say, look you're not really looking at black families as good candidates for black children, and instead you are placing these children with white families and that's like an emigration out and it's not good for their mental health and their identity, et cetera. So, after that, there's a huge shift in adoption practice really to not consider white families and to consider black families and black parents much more seriously. So, there's all of that going on. The same is happening with sort of the Indian adoption project, which is to place Native American children with white families. Then after the Black Social Workers Association statement, there is the Native American tribe say, hey, we don't want this out migration of children and we should have sovereignty over our own tribe and what happens to our children. That ends up in ICWA. These are things that are happening, not about disability, but definitely about special needs children, because they have special needs for placement.

Emma Wathen: I don't remember which chapter this was in, and it might have been an instance where something was being discussed in theory that didn't trickle down into practice. But I feel like you referenced, they were an adoption professional, some sort of a specialist who was speculating about whether or not, around this subject of matching and fitting children with families, that perhaps a child with emotional or behavioral disturbances would be less disruptive in a working class black family as opposed to like a white middle class environment.

Sandy Sufian: Yes, that's right. There's a kind of, maybe I'm overstating this, a flurry of studies around in the late 60s. Franklin and Masaryk is what you're talking about. Then there's another study by Chamberlain, I think, about who are the best parents that will adopt children with disabilities, right? What they find is it's actually not the typical family they're thinking that's so ideal for all children, the white middle class intact heterosexual family, but rather those families that are sort of have what would be considered a

disqualifying character to them, previously. So they might be a single woman, they might be not middle class, maybe lower middle class, or even, you know, not poverty, but working class. These are the groups of parents that have not been seriously considered until this time, when there is really starting to be more and more kids going into foster care, and also the opening of considering children with impairments, children with disabilities in the late 60s for consideration for adoption at all. So that's the 60s. There is a flurry of studies to say who is it that's going to do this? And they find that the highly educated white family actually doesn't want a child with a disability, or if they're going to consider it, there's a hierarchy of what they would consider in terms of disability, I think that's what you're talking about that study, correct? It's a very famous study. There's two parts to the Franklin Masaryk study. And then later, there's more studies about, again, who's going to adopt these children, and they look at those studies to decide who then to recruit for these children. So that's a little bit later, but the agencies then take the results of those studies and say, hey, you know, we can consider all these different parents. In fact, those are the ones that we should actually recruit because they're gonna be much more open and willing to adopt these children with disabilities.

Emma Wathen: Yeah, expanding on this influx that you mentioned of more adopted children are coming from the foster care system by the 1970s, specifically within some of the communities you mentioned. So, before the Indian Child Welfare Act was passed in 1978, you have some estimate close to like 35% of Native American children are being removed from their families and put into like foster care, adoption, and institutions. So, I was wondering, how did this shift in adoption demographics and particularly the disproportionate number of children of color in foster care impact conceptualizations of risk, disability, and adoptability in child welfare and practice during this time period?

Sandy Sufian: Changes in demographics significantly affect the discourses around risk and adoption practices and policy. The crisis in foster care is that there's what's called foster drift, which is when children go from foster care home to foster care home to foster care home, and they're in foster care for so long. Either they can't be reunified with their family, or they are not adopted yet. There's also this whole issue of what's called waiting children. So, you know, the relinquishment has to be gotten by the biological mother. And so, if there is a problem getting relinquishment, legal relinquishment, the child is sort of sitting in foster care. So, there's that whole problem. And this, I mean, these are the politics of foster care. But as that's happening, there's a shift to say that the foster care system itself is a risk factor for disability for these children, because they will have acquired disabilities, emotional, mostly, some mental, but they're acquiring disabilities while they are in the foster care system because of the inadequacies of the bureaucracies and just the whole politics around which they are coming into the foster care system. So, there's that.

In 80s, there's the AIDS crisis. You have children that are called chronic care children, children with chronic care needs. Many of them are AIDS orphans who might have HIV. Still again, you have all this divestment. You know, Reagan's just a whole thing in of himself that causes so many issues. So, there are new kinds of children that are coming into the foster care system, which creates a real push of adoption agencies to focus what's called on special needs adoption. That becomes a huge focus on the policy side, and it's given that name. So, there are shifts around risk and being at risk, having structural and systemic issues producing risk, as opposed to the children having inherent risk. At the same time, there is the pathologization of poverty, which kind of allows some agencies and some adoption professionals to say that these children are inherently at risk, risky, or damaged. There's a whole cultural discourse in the Reagan era around that, particularly children of color. So that's when those things sort of sitting at the same time. Those two conceptions around risk. This causes shifts in policies. There's the Adoption Assistance Act in 1980,

which federalizes subsidies, incentives for parents to adopt children with disabilities, but also any special needs—what's called special needs children. There are more intensified kinds of training programs and projects for caseworkers. There's the emergence of Master of Social Work programs that are particularly focused on special needs adoptions, where people get specific training. There's a slew of kinds of responses. And there's also federal acts that start to allow agencies to place children of color in white families again only after they cannot find a family of color to place these children with, because there's just so many children.

Kelsey Henry: Yeah. Kind of building on this question about shifts in adoption demographics towards disproportionately being children who are coming out of the foster care system, which are disproportionately children of color, black children. I'm wondering if you can say a little bit more, both like pre 1970s and 1980s—you can give us a little bit of a prehistory, but if you want to stay in the 70s and 80s, you're welcome to—about the close proximity between children of color and disabled children in what was first the hard to place category that became the special needs category. Can you say a bit more about how children of color and disabled children were not mutually exclusive categories in the realm of adoption, but were actually really constituted?

Sandy Sufian: Sure. So, I mean, that's really in the 70s and 80s, but that starts to, I think, solidify. But certainly, the hard to place is all the same children: older siblings, minority children, handicapped children. I do have a little section in the book about how at least this book is a national level book. So, it's very broad speaking, I would say and therefore I didn't go through agency records where I went through rosters that showed me which kids were what. I wasn't looking at that those specifics. I think that work still needs to be done. It has to be done per agency. It's a hard thing to do, first of all, to gain access to that stuff. I tried to gain access to some but wasn't successful. In any case, I was trying to figure out if a child was categorized as a minority child, did they have a disability? Could they have a disability as well? And from what I can gather, if you were categorized as a minority child, you did not have a disability. You were a what was considered a healthy minority child, and then handicapped children were children of all colors of all ages who were disabled. So, their main characteristic was being disabled. They could be a sibling, but if they had a disability, they were considered handicapped. Same for special needs. Now, where it's interesting as a historian is that the policies around special needs adoptions is that the entire class of special needs children require special needs for placement. Sometimes a little bit different, but on the whole, in general, it's harder to find parents for them, which is huge. A major problem that's even present today is finding parents who will adopt them. So, a lot of their history, their policy histories are the same. And the outcomes are the same—not entirely. There are more programs for children of color from what I can gather. There are certainly more scholarships about those programs. But these laws are all addressed to this huge category, big category of children. So, they're not really disaggregated. And then when, particularly in the 80s, you have such a racialized cultural discourse and a discourse around damage and fitness and those intersections, you might have what's considered a healthy minority child who ends up in foster care and then acquires an emotional disability, right? And so then they're both. In that way, they're co-constituted simply by virtue of being exposed to similar kinds of systems.

Emma Wathen: Yeah, no, that is both fascinating and disheartening to hear about this sometimes, like this erasure of race within this category of what we call handicapped children, as well as sometimes this lack of recognition of the way in which these categories might intersect and then how that lack of recognition might have impacted these children. And I think that speaks to maybe some of the limitations, even within this period of greater inclusivity that we were talking about. So, you mentioned that by the end of the 1990s, that

the possibilities for inclusion were still partial. And in chapter four, you write, professionals framed the adoption of children with disabilities as a personal and private mission for parents rather than a broader societal concern. Can you say more about the persistent barriers, both structural and conceptual, that limited the possibility of inclusion?

Sandy Sufian: Yeah. I mean, a lot of these training programs, for example, for social workers, it's addressing disability stigma for caseworkers, or trying to reframe children's attributes if they have disabilities in a way that's sort of like they're like every child. It's very individualistic. So, there's an appeal to parents and an appeal to caseworkers to address stigma, which is a serious thing, but it still leaves the idea that it's your choice if you want to have these children in your family or not. And that makes sense because we have a very individualized idea around family building. But if we were to look at social and structural kinds of policies to, or barriers even, we would want to think about health care and addressing health care and access to health care, right, for families, particularly in the 80s and 90s, this is pre-ACA.

Just the ability to have access to medical care for children with disabilities is really important for making it possible to have parents who even want to have these children and raise them. It's not so different for biological children right because a lot of times, these biological parents are putting their kids up for adoption if they have a disability and they can't afford the insurance or they're dropped from their insurance, right? So, it goes both ways. If you wanted to address equity and access, for example, with health care, you would want the caseworkers and the adoption agencies to be advocates for universal care, but they're not. They very much frame this as about the adoption triad, the biological mother, the parent, the applicants, and the child. Certainly, some of them could be disability rights advocates. I don't know in particular, but I didn't find any evidence or mention of social movement pushes in the adoption agency files or Child Welfare Week of America files, right? It's very much about your client, the child, parents, the biological mother.

I think that's what I meant is if you're not addressing these wider structural issues, the problem's still gonna remain because it's really about how do we think about—and I write this in the epilogue—I really see the family and access to family as a disability right. It's not just transportation and employment, which are really important things, but it's access to family. That's the beginning of any acceptance of people with disabilities in America. That's the first point of entryway. And if we don't have that, and we can't think about ways to address that issue, I'm not sure how our children and adults with disabilities can ever be like fully accepted in our society. I don't know, maybe I'm wrong, but I think it's a serious issue. The reason why I say that the trajectory is a partial inclusion, it ends with partial inclusion, is because we haven't addressed this issue of access to family. And what does that mean? What do we need? What supports do we need to have access to family whereby children with disabilities are considered just as great as any other child to have in your family? It's still left up to the parents, the parent applicants, to kind of decide. Even now it's left up to biological parents. The biological mother now, for many years, not just recently, has the ability to decide the adoptive parents, right? So, she may have prejudice against disabled applicants. The agency can't discriminate under the ADA in adoption, domestic adoption, but the birth mother can, right? So I think that's what I was talking about is like it's still kind of an individualized thing and it's because we think of the family as the private sphere. But I think what adoption does is show us how it's not just the private sphere. There are major public ramifications and it's really a public sphere issue. Things can totally change as the government policies change, like we see with this proliferation in the 70s and then Reagan comes, and he undermines it all, right? So, how do we square that? It's not sustainable.

Kelsey Henry: [01:13:31] I loved the way that you were drawing these connections between access to family as a disability right, like inclusion, the extent to which disabled children, disabled people are included in families and considered in family building reflects fairly comprehensively on their access to social and political citizenship. That perhaps it makes sense historically and contemporarily to downscale our analysis somewhat and look to the family as a battleground in which social and political citizenship is being contested from childhood, from birth. I thought that that was such a brilliant argument. And I think that it ties into one of your most provocative claims that, and this is a direct quote: “the story of disability and adoption uncovers how disability operates as a fundamental category in the making of the American family. That this story helps us rethink what constitutes the American family itself.” I'd love to hear a little bit more about what is it about the figure of the disabled child, particularly the inclusion or exclusion of a non-biological disabled child in adoptive family building that reveals the internal logic and also the limits of love and kinship and belonging in the 20th century that extends far beyond a history of adoptive family building that says so much about the family in America in the 20th century.

Sandy Sufian: I think as notions of the American family and who can be constituted in an American family changed over the 20th century, we see the concomitant liberalization of adoptability, of a concept of adoptability. They go hand in hand. It's just a really concrete way and case to look at it. I absolutely believe that this is a study around belonging in a family. Pre-World War II, and even now—this is like a little vignette—when people have children, there is almost always a push of certain people to say like, oh, they have your eyelashes. Oh, they have your fingers. Oh, that. And I hate that. It's like a pet peeve because what it means is that in order to belong in the family, they have to have some sort of physical resonance or physical similarity. That's what pre-Second World War adoption matching was all about, right? Is that you had to look like your parents. Like it's almost mandated. And sometimes I'll look, and I'll say like, they don't. They really don't look like their parents and that's okay. They don't have to look like their parents. They don't have to be like their parents. They can be themselves, right? But we don't, we still don't really allow for that very well culturally. And so, by tracing these kinds of this notion of who is eligible to be in a family, which parents are eligible to adopt we see a sort of very grounded intentionality to this family building that I do think helps us really think about who is belonging in an American family and what's the ideal versus what's the reality.

There is also this genetic tie thing, right? There's an assumption that it's best to be with your biological family. I mean, that's okay. Sometimes it is great to be with your biological family, but sometimes biological families suck. Sometimes it's not best to be with your biological family. There are cases when it's not best, and I think we have to just allow children and parents of whatever kind—our current debates around gay citizens being parents and the laws, state laws around that. That's all about who are we allowing to belong in what we picture as a family? And for what reasons? What reason? And I do think this history of love, where love fits in the family, and who's giving love, and who's receiving love is also really important, and that also changes. And we see that in adoption discussions very explicitly. That's how I see this book sort of having import outside of adoption.

Emma Wathen: This is taking a bit of a pivot here. But earlier in our interview, at the beginning of our interview, you mentioned Paul Longmore being one of the first figures you encountered on your journey into disability history. And in your epilogue, you mentioned that your book is dedicated to him, in part, because of his defense of historical work that provides a usable past to people with disabilities in the hopes of creating more accessible futures for them. Can you say more about how your work might provide a usable past for disabled children, adoptive parents, and adoption policymakers?

Sandy Sufian: I think it has to do with providing models around programs that facilitate, like that second part of the book, the adoption of children with disabilities or the integration of disabled children into biological families. The considerations that, or as Kelsey phrased it, the calculations that are still happening, we can look at how those calculations are contingent. Right? Contingent of time, place, pre-war and post-war technologies, divestment, investment, etc. It's a multi-layered kind of thing, which made this book very difficult to write, just keeping all the layers up in the air at the same time and considered.

So, considering all these categories of children together, what does that mean? How does that help us? How does that not help us? That's what I meant. But also, Paul was a very special person to me. I was very close with him. He was one of my first disability mentors. He was—sorry—he was the first person who really said, Sandy, this book is important. I got a lot of what are you talking about? You know, I started this project in 2008. Nobody was working on family at all in disability history. I was a Middle Eastern historian. What am I doing trying to do American history? But he was just like, you can do it. I spoke to him every day from the archives. And I would say, oh my god you aren't going to believe it. I found something by Bill Cosby. Bill Cosby was the celebrity for family builders of adoption, which was this adoption program specifically for disabled children. And he would be like, be very careful around Bill Cosby. But I would sort of process all the documents every night when I came back to my hotel from the archive with him. And so that's also why I dedicated it to.

Emma Wathen: And he was right. This is an amazing book. If a giant like Paul Longmore says that it's amazing, I think that that makes it even more amazing.

Sandy Sufian: Well, he said it before I even wrote a word. He just thought, oh, this is a good topic. This has fruitful potential. Let's put it that way. You know, he didn't get to see this book published. I can't remember if he even read anything that I wrote. I don't think he saw even the manuscript.

Kelsey Henry: And yet his legacy is so present in this book in the way that you're thinking about a usable past and the way that what you were saying about how the study of history encourages us to think about contingency, and what's so brilliant about thinking carefully about contingency and the ways that the risk adoption disability triad, for example, and the calculus surrounding that all of the different historically contingent and conditional factors that went into reshaping the relationship between those categories over time is a fantastic springboard for thinking otherwise. Like drawing attention to contingency historically for policy makers, disabled parents, disabled people in the present encourages us to think about how things could be conceived of differently because they have been conceived of differently. I think that's one of the most important things that history does for us is drawing this relationship between historical contingency and contingencies in the present that we can reimagine and reconfigure these relationships.

Sandy Sufian: Yes, absolutely. And I also wanted towards the end of writing this book, which was a very long process, I wanted to make a case that this is a history that matters. Like you would think, oh, it's some small little thing. But this is like for children with disabilities who have been adopted, who maybe are now adults or even teenagers or whatever, for adopted parents who have adopted disabled children, they have a history. There is a history to this, right? And they're not just these individual units or lists. They are part of this much larger project around what an American family looks like and what their place in that is. They do have, like you were saying, Kelsey, they have a place in social citizenship, right? We need to name it explicitly and analyze it explicitly. And Paul was just, I mean, that was him. He just used a lot of jokes and had a good sense of humor, more

than me. But that was what he was fighting for. I am so certain that he would have been so, so proud of this book.

Sandy Sufian: Thank you.

Emma Wathen: Sandy, this has been such a phenomenal conversation. I have learned so much in dialogue with you. I can't wait to publish this. Really quickly, is there anything else exciting on the horizon, like new projects of any kind that you wanna share with our listeners before we say goodbye?

Sandy Sufian: I am actually using my historical skills in clinical research right now, which is totally odd. So, for the past five years, I've been working on sexual reproductive health issues for women with chronic illness and having their input into what are priorities for them to study and to research. From that work, I'm working right now on menopause and lung function, but also menopause and just all these different things that we have. And doing a lot of qualitative interviewing and trying to get insight into how, first of all, the concept of quality of life is much larger and includes things beyond what quality of life researchers talk about. But I'm really interested in embodied knowledge of these women and what kind of experiential expertise they offer us, and how that can be put towards studying things like menopause, finishing up a study on menstruation and chronic illness. So that's kind of what I'm doing.

I'm learning how to do clinical research which is a totally different beast, but needs historical skills, I have found. It really does. In this weird application, but it needs it because we think of different kinds of questions than clinical researchers. And so, it's really helpful to be at the table. But then, if and when I'm ready to return to traditional historical projects, I really would like to do this. I've done all the research for the adoption science book. I literally just have to sit down and write it and learn history of psychiatry and psychology, mostly, because it's very steeped in that. Yeah so, I have all the documents. It's just kind of waiting to have the time to do that. I'm trying to intervene with disability history and disability studies kinds of sensibilities and questions and perspectives in clinical research right now. I know, it's totally weird.

Kelsey Henry: No, it's so important. That's vitally important work.

Sandy Sufian: Yeah, that's just so not what I expected to do at all.

Kelsey Henry: But that seems to be a trend or a pattern for you in your trajectory, so much dexterity. And I think it's brave, it's exciting to move in new directions from project to project. And absolutely bringing a historical perspective, via medical history in clinical spaces, in clinical studies is so exciting. Wow, I just, I can't wait. I can't wait for what's next.

Sandy Sufian: Oh, thank you. Yeah, so I'm doing that, this new work and it's a big learning curve, but it is interesting.

Kelsey Henry: Thank you so much for joining us, Sandy. We're really excited to share this episode with everyone.

Sandy Sufian: Thank you for having me. This was a wonderful discussion and I really appreciate your thoughtful questions. I hope I was able to give a window into what my book and my work is about.

Emma Wathen: You did, and it was a pleasure.

Sandy Sufian: Pleasure for me, too.