

**Disability History Association Podcast**  
**Hosts: Caroline Lieffers and Kelsey Henry**  
**Interview with Dr. Allison Carey, Dr. Pamela Block, and Dr. Richard Scotch**  
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**Caroline Lieffers:** Hello and welcome to another episode of the Disability History Association podcast. I'm Caroline Lieffers.

**Kelsey Henry:** And I'm Kelsey Henry.

**Caroline Lieffers:** And today it's our pleasure to have as our guests: Allison Carey, Pamela Block, and Richard Scotch. They are the authors of *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities*, published in 2020 by Temple University Press. Thank you all so much for joining us today.

**Pamela Block:** Thanks for having us.

**Caroline Lieffers:** It's a pleasure. Can we just start by asking each of you to introduce yourself with a few sentences? Maybe Allison, you could start us off.

**Allison Carey:** Sure, So I'm Allison Carey. I'm a professor of sociology in the Department of Sociology and Anthropology at Shippensburg University, which is a Pennsylvania school.

**Pamela Block:** I'm Pamela Block. I'm a disability anthropologist at Western University in London, Ontario.

**Richard Scotch:** And I'm Richard Scotch. I'm a sociologist. I teach sociology and public policy at the University of Texas at Dallas.

**Kelsey Henry:** So wonderful to have you all here today. To get us started, just easing into the conversation, we'd love to hear how you arrived at this topic of activism by parents of children with disabilities. Where did the project begin? And then how did you find your way to each other? Like how did this turn into a collaborative project?

**Richard Scotch:** Well, we have all been studying activist parents through much of our various academic careers in different ways. But I think the project, probably, I was the one who got it started as a project per se. I've known Allison and Pam a long time. We're all active in the Society for Disability Studies, and Allison and I are involved with the sociology, disability and society section. But I got interested, I guess there were two points that got me interested in this topic. One was as an early member of the Society for Disability Studies, there were some debates over whether parents were part of the disability rights movement or not. This goes back into the 80s and 90s, which was an interesting debate. Not always a civil debate, but a lively debate. But I think in terms of the particular project, I was on the editorial board for the Encyclopedia of American Disability History that Susan Burch edited. And I was responsible for some of the entries that dealt with public policies, but also some of the disability organizations, and as I was looking at the history of some of the parent organizations, I discovered that there had really not been much scholarship on this and yet I knew that Allison had done a lot of work on people with developmental disabilities, intellectual disabilities. So, we talked about maybe pursuing this and very early in the project got Pam involved as well, who's done a lot of work on families affected by autism. We talked about it for a few years and put together a book proposal and the rest is disability history, I guess.

**Kelsey Henry:** I'm really curious to hear more about what the collaborative writing process was like for the three of you. Compared to other fields in the humanities or the social sciences, I've noticed a lot more scholarly output within disability studies and disability history that moves away from a single authored manuscript—beyond just producing anthologies, but actually collaboratively writing texts that seem to be in one voice, but there are multiple authors that go into the production. So, I'm curious to hear a little bit more about how that unfolded for the three of you.

**Richard Scotch:** Let me start and let my colleagues continue. Allison and I have been working on projects together for quite a long time. We edited a book together. We've worked on various projects and been in a lot of contact. And Pam has also interacted with each of us in different ways. So, the collaboration potential was already there, but I think for this particular project, we each brought in some particular set of interests and knowledge that lent itself to a division of labor, not just in terms of the types of impairment that we have focused on, but also on different aspects of activism.

**Allison Carey:** Yeah, I'll just add a little bit that we did. So, we each took one of the chapters in the beginning looking at a specific group and as we went into that we talked about what themes and how we might want to structure the chapters. We created a basic structure for our chapters ahead of time and we knew some of the themes that we wanted to hit and similarly with the second half of the book we were talking about the different major cross-cutting issues to hit, and then we all edited each other's chapters and gave insight. Then, I did a final run through where I did kind of smooth out - is this the wrong word, right? Cause it makes it sound like the chapters were rough in some way. I did a lot of editing, not of the concepts, but sometimes of the language so that it sounded a little bit more like it was a single voice.

**Kelsey Henry:** Oh, I would love to circle back to something that Richard mentioned about early work with the Society for Disability Studies and how contentious this question of whether or not parents are a part of the disability rights movement, if those voices and those stories should be centered in disability studies or disability history. I'd love to hear more about hesitations that the three of you experienced about approaching such a really historically fraught, complex, emotionally charged, contentious area, not only in disability rights movements, but within the field of disability studies when you chose to collaborate on this project together?

**Richard Scotch:** You raise a good question, but I think it kind of over emphasizes conflict. I'm not sure, I mean, there were conflicts in SDS. I was the executive officer for a while. There was a lot of conflict in it. There were a lot of disagreements, legitimate ones, but I think not so much about scholarship, perhaps about who ought to be leading and what the role of non-disabled scholars ought to be vis-a-vis people with disabilities themselves. And that sort of drew in the whole issue of parents. But I don't think that affected us at all in the kind of work we've been doing, and I haven't heard anyone really challenge the legitimacy of what we've been doing. Maybe I just don't know about it because I'm too self-absorbed, but I think these are stories that need to be told. And since we're not telling stories about ourselves so much, this whole question of who can legitimately talk about what didn't really come up. I don't know, did it for either of you?

**Pamela Block:** I don't—not in this time, but I do want to kind of acknowledge that historically there were tensions in disability studies and absences, right? Like when Allison and I were first emerging scholars and doing research on people with intellectual disability, you know, there were very few people within disability studies that were doing that, and there were very few people with intellectual disabilities involved in disability studies, right? And it's still pretty rare. So, there was definitely a sense that we were outside of the mainstream, and also there have been moments in disability studies where more cultural studies have been more dominant and other historical times when social sciences have been more present. There's always a little bit, and tensions between

disabled people and non-disabled people in representation. I mean, those are all there, or were there, historically. I mean, there's always tensions continuing, but I agree. We didn't really experience it for this book. I was really moved to join the project. It was right around the time my mom had passed away when Richard and Allison contacted me. And my mom is one of these people who was very involved in parent organizations and movements for much of my sister's life. But by the end of her life, she and my sister together, and then they kind of got me into it as well, were very clearly aligned with disability activist movements too. And I just thought that was really interesting and noteworthy, and I wanted to honor my mom and that trajectory that she traveled through this book.

**Caroline Lieffers:** Thank you so much for sharing that. And Pamela, I really, really appreciate what you just said. That's really important. I have a question about the kind of disciplines that you are coming out of. Although your book focuses a lot on the history of disability activism, none of you are specifically working out of history departments or history programs. And so, we're just sort of curious about why history, right? What led you to take this approach? Why was that important to you? And how did you find that meshed or maybe enlarged some of the disciplines or methodologies that you're trained in or that you would normally use in your work? Love to hear more about that.

**Allison Carey:** I was trained in a sociology program in comparative historical study. For me, sociology, the study of society, understanding how social structure impacts us needs to always be embedded in history. I took a statistical methods class. I took qualitative methods, and I did historical comparative methods. And I am kind of a history wannabe. (laughs) I like hanging with historians and talking to each other.

**Pamela Block:** (laughs) Our articles are side by side in that Susan Burch—who is the co-author—

**Allison Carey:** Michael Rembis.

**Pamela Block:** Michael Rembis, yes. So, seeing our work side by side, you could really see the influence. I also, in anthropology, both of my undergraduate mentor and my graduate mentor were both doing this intersection of anthropology and history that I think was always very methodologically important to me.

**Richard Scotch:** And I would just echo what Pam and Allison said. I, as an undergraduate, took as many history classes as I did sociology classes. They actually were often better taught and more interesting. But I've been doing history all along. It just wasn't history, perhaps, as a historian might have done it. But my dissertation was a history. Most of my book projects or articles have been histories. I was never trained in historiography, and so perhaps I was not doing it the way a historian might. But I have always been fascinated by that perspective on how political conflicts develop, on how public policy develops. I won't say I reject, but I'm not a big fan of this distinction that there is this discipline over here and there's other discipline over there, and sometimes they connect. I just think it's all part of what we're doing and whether it's humanities or social science, I'll leave to you to decide. I come from a department full of people who do comparative historical work.

**Caroline Lieffers:** That's really interesting to hear. And I wonder if Kelsey, maybe you being from American studies would be nodding enthusiastically about some of the stuff about breaking down those disciplinary barriers.

**Kelsey Henry:** Yeah, I like to say that I've never been disciplined in my thinking or my training, even though that's not entirely true anymore. Like I did get the master's in history of science and medicine so now I say that I have a historian's spine, but I have a lot of other things going on. Yeah, in undergrad I majored in two interdisciplinary fields.

I did American Studies and Feminist Gender and Sexuality Studies. And I similarly appreciate the freedom of being able to reach for a variety of methods just based on what is the research question, what is the research question asking for organically in terms of methods that would suit it and not feeling overly hemmed in by this idea that only some people have the right to certain methods based on foundational training. I've never put a whole lot of stock in that for sure.

**Richard Scotch:** No, no, my work is mainly working off secondary sources. I haven't done a lot of work with primary sources except for my dissertation, which was interviews and archives and contemporaneous accounts. But some of the early collaboration I did with Allison involved memoirs, and which she did some really thoughtful analyses of and what that tells us about disability. So, she and Pam have worked a lot with more primary sources, but not so much me.

**Kelsey Henry:** Well, looking at the finished product, it certainly seems like each of your historical sensibilities melded and meshed very effectively together, and we're benefiting from the finished product for sure. So, speaking of history, can you say a little bit more about the earliest history of parent activism? So, where did this begin? How did it begin to grow? And what were some of the earliest objectives, imperatives and achievements for the first sort of cohort of parent activists?

**Richard Scotch:** Well, let me first say that there have been parent activists as long as there's been disability. Parents have always advocated on behalf of their children. So, what we're looking at more as organized activism is advocacy organizations in particular, social movement organizations, we would call them in sociology. And so, and there have been disability organizations of parents, you know, for going back into the 19th century. We started looking at some of the organizations that formed after World War II, and they had some notable characteristics. They were political. They were often fairly privileged, upper-middle-class white people. They were part of the whole celebration of motherhood and of families and of child-rearing that was from that era. As I said, I had noticed some of this as I was writing these entries for this encyclopedia. And I was struck by the commonality across several organizations that were started by parents in suburbs, often of New York, parents who often had certain kinds of connections with people who exercised a lot of power. And they were upset that their kids couldn't go to school because in that era children were largely consigned to institutions, and these activists rejected that. They sort of found each other and made some alliances, some more fortunate than others in retrospect, but it was a period of early activism that was more collective in nature.

So, answering your question on that level, a lot of it got started in the post-World War II era, and a lot of it in particular around the East Coast cities. Many of these were parents of kids who had complex medical conditions, but also intellectual disabilities, other kinds of physical and mental disabilities. But this whole idea that you would fight to get your kid into a school, and you would fight to get resources put into biomedical research to try to deal with, perhaps preventing some of these conditions, those weren't always consistent with one another, but those were two of the elements of a number of these early organizations that I looked at.

**Caroline Lieffers:** That's really interesting, thank you. You explain in this chapter on intellectual disability that I'll read you the quote, "in many ways, the success of the parents' movement also created some of its most enduring problems." I thought that was a really powerful way of framing this. Would you mind explaining a little bit more about what that means?

**Allison Carey:** So, we look at what parents were aiming for and then the ways that it became institutionalized back in the 60s and 70s. Parents, as Richard was saying, they were confronting a situation where their children weren't getting education and so they

were looking to create these educational opportunities and they did that largely by creating special classes and often parents themselves were running those classes right, and then when we get the IDEA passed, and it's national legislation, and it's amazing, right? And it confers all children the right to education, but the model at that point, even though the words least restrictive environment are built into the idea, the idea of that was still largely segregated classrooms and even special schools. So, you see this growth of the special school and special ed as tied to segregation, and now it's super hard for us to undo that because we have whole buildings and we have, right, and we need people who are trained in disability, but we've distinguished regular education from special education in a really polarized fashion that is hard to undo. And we see the same thing in community services. So, parents who were fighting to deinstitutionalize—and they did this incredible work of building group homes and vocational services and community treatment to some degree, right? And so, but again, often that was segregated. So rather than being big institutions, now we had smaller group homes and we had smaller day programs and we had smaller vocational rehab programs, but they were all still run by able-bodied staff and people's worlds would be moving from one disability program to another disability program. They were still all defined by their disability, assumed that they were best being with people with disabilities.

And so again, when we try to move towards meaningful community inclusion, we have to rethink that whole frame. And that includes rethinking the way the money goes, right? If the money goes to the agencies, then that makes it really hard for us to challenge those agencies to build community integration. So, we see programs like Money Follows the Person. We need to challenge the hierarchy of the staff and whether the staff are there as medical professionals or ABA professionals and those things aren't bad, right? But people should just be able to enjoy the things that they want to enjoy without constantly having intervention and having, again, that disability really control their whole life. And so, what parents achieved, I mean, it's truly remarkable to me when people say nothing can change and I say, oh, no, no, no, right? Like there were huge institutions. People died really early. Children were separated from their families. We have changed that, right? So, disability history shows the remarkable ability for us to change and improve society. But yet, these problems that we're dealing with now, they've been institutionalized in what was progressive change at the time. But now we want more. And it's hard to get because we're embedded in paradigms from the 60s and 70s.

**Caroline Lieffers:** It's a really, really interesting way of discussing this issue is kind of putting that historical lens over it and seeing the way something that was progressive back at that time is now more conservative. That's yeah, thank you for that. That's really clarifying. I really, really appreciate that. I also have to say how much I enjoyed and appreciated the chapter about the history of parent advocacy around mental illness. This was frankly something I did not know much about before I picked up this book. So, thank you just for the work there. This story follows a kind of similar trajectory is what we've described with the history of perhaps intellectual disability, but a little bit later in time and with its own elements. One of the tensions that is at the center of this chapter about mental illness is about sort of a conflict or some tensions or friction between the National Alliance on Mental Illness and activism led by people with disabilities, and I was wondering if you could just talk a little bit more about that.

**Richard Scotch:** Sure. Well, a lot of mental illnesses don't really manifest themselves until adolescence or young adulthood, and so the kind of tensions around adolescence and young adulthood for any family are present in families where the child is affected by a psychiatric condition. So, it's a little different, I think. The dynamics are different from a condition that is observable and that leads to a diagnosis in early childhood or not so early childhood, but not quite that late. But also, from a legal standpoint, when you're dealing with adults—when people who are legally adults, who legally have the right to make decisions about their own situation—decide whether to accept treatment or not. Because the psychiatric nominee and some of these other conditions, these other

organizations came about later historically, when the rights to refuse treatment had been quite well established as the result of the whole due process revolution of the 60s. This put a conflict between organizations like NAMI that historically mainly represented parents and organizations of people who were themselves being diagnosed as having a psychiatric condition, who were being pushed into institutions or not being pushed into institutions. And so that kind of conflict between these adult children or these late adolescent children and their parents was quite pronounced. Now NAMI was, like some of these earlier organizations, pushing for biomedical interventions, but one of the distinctive things about it is that it got a lot of funding from the pharmaceutical industry. In fact, I think parents in NAMI and some of the other mental health advocacy groups of parents actually embrace the medical model. We talk, we haven't talked about it yet today, but certainly in the literature, there's a lot of discussion about the medical model versus the social model of disability. In many cases, the parents of children with psychiatric diagnoses embraced the medical model because they were being blamed by mental health professionals and rehabilitation professionals for the conditions of their children. And so, they wanted to say, "hey, it's not us." It's something that's wired into them, and we need to treat those with drugs. Some of this gets into, I think Pam could talk about this in terms of the autism spectrum as well, but I think NAMI, perhaps more than some of the other advocacy groups, really embraced this biomedical model of mental illness and really was quite enamored with the idea of treating it with medication. Whereas most of what they call the psychiatric survivors movement of people who were diagnosed and reject the diagnosis are people who want to emphasize that they cannot be forced to accept these medications, that they cannot be forced to undergo treatment, that they cannot be forced to be restricted. And that debate goes on today. NAMI is, I think, a little more ambivalent about that than they were early on. There are—and it varies kind of by community, I think, as well as at the national level—in its early days, NAMI was an enthusiastic supporter of laws that allow involuntary treatment, whereas the psychiatric survivors always rejected that, always emphasized the rights of people to refuse treatment. When you're talking about people who are legally adults, that's not a trivial thing. It may be harder for a 10 year old to say, I don't want the medicine, but for a 20 year old, it's much a different situation.

**Kelsey Henry:** Yes, and Richard, you gave me so much to think about. My mind went in several different directions. I'd like to hear a little bit more, because you mentioned it briefly, about this topic of parent blame or mother blaming that came up in the introduction of the book. And I'd love to hear a little bit more from either any of you, anyone who feels compelled to talk on this, you have these different case studies in part one of the book, parent activism as it concerned intellectual disability, psychiatric diagnosis, autistic identity and physical disabilities. I'm curious to hear about within each of these case studies and different kinds of disability, how did the presence of mother blaming or parent blaming for child disability diagnoses shape different trajectories of parent activism in terms of what parents were advocating for, what they saw themselves as fighting or up against?

**Richard Scotch:** Pam does have a lot to say about this, but I'll just say briefly that a lot of self-advocates certainly reject the authority of medical professionals, and a number of parents do as well, but a number of parents accept the judgments of medical professions, but I think that's all tied in with a number of other movements: with the women's movement, with the self-care movement, with a lot of what was going on in the late 60s and 70s. I think Pam probably has lots to say on this, and let me pass this over to her.

**Pamela Block:** It certainly has a life of its own in relation to movements involving autistic parents and service providers, clinician approaches to autism. The idea that "cold" mothers were to blame and caused autism was of course embedded in the early scientific work about autism and was not shed for a very long time, to the point where many people didn't even get the diagnosis because, well, for several reasons, but that

was one of the reasons. They didn't see that it could be autism if that wasn't present, instead of questioning whether that really was something that caused autism. But in terms of the case of autism, the parent blaming goes beyond just that particular example, right? Like parents are blamed for exposing their children to toxic environments or toxic foods or for not exposing them to certain therapies. No matter what autism parents do or don't do, there's going to be somebody passionately blaming them and saying that they have ruined their child forever, because they haven't done this intervention or have chosen to use another intervention. Often, parents do that to each other, and also different clinicians are advocating for their particular approaches, and it becomes a very confusing and upsetting environment for new parents who are just trying to navigate the system. It's something that was less present when my sister was born and being identified as disabled. She wasn't identified as autistic until she was an adult. And she was, again, one of those people that was identified as having an intellectual disability that was seen as a more hopeful diagnosis.

People had interventions in the 60s and 70s for people with intellectual disabilities that didn't really develop specific interventions for autistic people until later. What that meant though, is that she dodged a lot of this kind of blame issue, right? My mom also was not targeted in that way. And my sister didn't have to deal with ABA and some of all of the other very confusing things that are either causing autism or are considered essential for treating autism. As you're aware, we have theories that from mother blaming, it went to the toxic environment, and then from the toxic environment, it went to genetic influences. They're still sort of there. Like big money is going to targeting genetic causes and also vaccines—the idea that vaccines causing, that's sort of a specific subset of the environmental toxic or like toxic exposures theories. You know, I can imagine the experiences of parents having to navigate through all this and try to figure out a way. And then you also have autistic activists now saying that some of these interventions and some of these theories are completely off, right? That the idea, that clinical ideas of what constitutes autism are wrong, and clinical interventions are not only wrong, but sometimes traumatizing and damaging to autistic people. So, then you have very heightened tensions between clinicians and parents and autistic activists that takes us to sort of what we have going on today.

**Allison Carey:** I could chime in and bring us back a little bit in terms of mother blame too. I think it's really interesting that Pam is talking about how mother blame pushes parents towards all of these treatments and interventions. If you go further back when you have eugenics, right, then you have a mother blame that's really based on genetics, on this idea of heredity, and that the family itself is implicated in a different way, and that's certainly helped to drive institutionalization. The idea that it wasn't just disability but that people with disabilities were innately problematic. They were criminal, they were sexually deviant, they were bound to be poor and so they needed to be segregated from society and that made it so hard for parents to be activists to talk about their child because if they reveal disability they were also potentially revealing something about themselves and their other children. So, they were told at times to institutionalize your child because this is going to be harmful for your other children. And so that level of mother blaming and parent blaming is just—it's interesting to think about how this idea of mother blame can play out really different ways in different historical eras and with different populations.

**Richard Scotch:** And that gets involved into race and ethnicity in major ways.

**Kelsey Henry:** In your book, you make the argument that parent activists are not a monolith. This is not a homogeneous population, there are divisions, not only based on which disabilities are we talking about, but also in terms of whether or not parents are more aligned with rights-based or justice-based goals, how that relates to differences in socioeconomic status or class, race, the racial makeup of a parent activist group or community. Can you say a little bit more about how socioeconomic status and race in

the histories that you were looking at informed parent activism and promoted kind of different values and different goals for parent activists who are coming from different class backgrounds and racial backgrounds. And then sort of tacked on to that question, can we map any of these divisions onto a progressive versus conservative political spectrum? Or is the story a little bit more complicated than that?

**Richard Scotch:** Early on for the groups I was studying, they were largely upper middle-class white people. So that doesn't mean that people of color and people of lower socioeconomic classes or marginalized ethnic groups were not advocating for their children, but they often didn't have the levers that these privileged people did. Some of the early activists that I looked at by reading their biographies or their autobiographies, you know, were wired into some of the leadership in political institutions and cultural institutions and business institutions. So that gave them a lot of resources and a lot of networks that enabled them. Often activism by other groups that relates to disability gets caught up into other struggles, whether it's racial struggles, whether it's class struggles, people who are affected by toxic environments, kids who have the same symptoms—the people of color are called intellectually disabled and mentally retarded, whereas the middle-class white kids are called learning disabled with the same test scores. So, it's class and race run all through this, but let me turn this over to Pam because I know she has a lot to say about this.

**Pamela Block:** Yeah, so we definitely see disparities across school systems and especially school systems that have predominantly white versus non-white populations in terms of the opportunities and supports that are available, even though we have these national laws, there were white people who had the resources to navigate the political and legal obstacles in order to advocate for their children. And so that's where we come to this difference between a rights-based approach, which excludes a lot of people who were never represented by those policies and laws who have been excluded and where, due to systemic racism and structural violence, have not been able to access the rights that they supposedly have that exist on paper but are not happening in society. So, understanding from the perspective of the disability justice activists who are primarily non-white, non-cis people who have intersectional identities and the disability justice movements created by and for these people who have been excluded from rights-based narratives and providing alternative ways to support each other to survive despite these structural inequalities and injustices. And so that's a very powerful movement that's happening now. And another thing that's happening is people are going back historically and revealing the erasures that have happened. This myth that autism is embodied by white boys, right? So now we understand that that was never true. It's just that's where people were looking. That's what they saw because that's what they were looking for, right? And as Richard said, the people with the exact same sets of symptoms being diagnosed in different ways. And in particular, diagnoses such as oppositional defiance disorder, for example, was being used in ways to surveil and control and restrict the freedoms of students of color. And then this flows into this whole notion of special ed to prison pipeline that many disabled students of color have experienced.

**Richard Scotch:** It's gendered as well.

**Pamela Block:** And gendered as well.

**Richard Scotch:** If you want to understand why now, after the American with Disabilities Act has been in place since 1990, the rate of economic inequality between people with disabilities and everybody else has not really changed at all. It's because of some of these kinds of class and race and gender relationships. People with disabilities structurally are at all these different disadvantages and have less leverage than relatively privileged families or children of these families with high amounts of cultural and social capital who can use these rights to claim participation and to claim access. But those access claims are not being made or not being effectively made by many



other, many, many more people.

**Pamela Block:** And some of these inequalities and structural racism is reproduced within the activist movements, in the parent movements, and in the amongst activists movements that are run by disabled people as well. And so, it's really an important thing that disability, the disability justice movement and disability justice activism activists are acknowledging and visibilizing this continued racism that is embedded within activist structures.

**Richard Scotch:** There's also, a lot of people don't like to talk about it, but a hierarchy within the disability community—that some people's impairments give them a lot better opportunities than other people's in terms of being able to claim access, in terms of being able to receive education, have access to employment, even have access to public facilities. You know, it's certainly tough getting around in a wheelchair, but a lot of the disability access laws have benefited wheelchair users more than they have people who have other kinds of conditions that may be affecting their communication or their mobility or their cognition or whatever.

**Caroline Lieffers:** That's really interesting. Before we move on to some of our next questions, I just wanted to swing back to something that Pam mentioned a couple questions ago. I was thinking about how our audience might not know what you mean by ABA when referring to autism. You have a great discussion of it in your book, but just for the sake of our audience, would you mind talking a little bit more about it? And actually, I think it maps really in interesting ways onto what we've just been talking about in terms of kind of normalization paradigms versus justice paradigms when it comes to talking about kids with disabilities. I'll just give you the floor to discuss ABA a little bit.

**Pamela Block:** Okay, so I'm not an expert, but I have done some writing about this recently. ABA is a particular form of intervention for autistic people that emerged from a methodology that was originally developed to address and intervene on boys who were feminine. And so, there was some pushback against this idea that you could deprogram boys who were feminine. The author of this, blanking on his name now—

**Allison Carey:**—Lovaas, right?

**Pamela Block:** Lovaas, yeah. So, ABA means applied behavior analysis. This methodology was created by Lovaas to address what was perceived as feminine behaviors in young boys and adolescent young men, but it was quickly moved from that population because it was seen as inhumane. I mean, just the whole idea of deprogramming people who are non-cis was seen as problematic. So, the methodology was then used for autistic children, and somehow those ethical quandaries just kind of disappeared for a while.

Applied behavior analysis is critiqued by autistic activists as being very controlling, as teaching passivity, as teaching someone to follow rules and orders in ways that are very dangerous. And in some forms of applied behavior analysis, the force of the pressure that's put on the child to conform to the orders of the therapist can get very extreme and very physical even. Extremes of applied behavior analysis might even involve cattle prodding and electric shocks. And that is still being used in a few settings actually, although, most practitioners now disavow those kinds of negative reinforcement and focus on the idea of positive reinforcement. But even the most benevolent forms of applied behavior analysis have with them a kind of surveillance and control that's very unsettling and is felt and perceived by the children. You know, people have recounted that to me, and I've read accounts of this. Just these systems in schools where teachers like track behavior and the students win, you know, the token systems and things like that are seen as very problematic. The idea of disciplining your body, using ABA to

discipline your body, quiet hands, quiet feet, listening ears, and there are these little models that get sent home with kids with all of these different things that they're supposed to remember to do with their bodies. It is the idea of sort of creating a well-behaved, seen but not heard kind of child. It's very problematic and also not comfortable for autistic people who need to move their bodies differently. And what's wrong with moving your body differently? What's wrong with moving or even vocalizing in non-normative ways? Why is there so much emphasis placed on creating this supposed normative way of being?

**Kelsey Henry:** And so much of what you were saying, Pam, resonates with me and I think is a helpful segue for thinking about tensions between parent activists and disabled activists. I grew up in a home with a sibling with a disability and a parent who was trying to figure out the best way to support her child. So my initial exposure points to disability were from the family perspective and it wasn't until I went to college and I took classes in disability studies that I was exposed to any critiques of ABA that were coming from autistic adults or even autistic teenagers who had been through ABA programs, and the ways that these programs do promote a kind of normalization or facilitate masking behavior in folks with autism that can install self-surveillance, everything that you were saying. I don't know. This is a lot about my personal trajectory, but it's just definitely informed my thinking when it comes to just the complexity here of people who, like parents, teachers, disabled activists, were just their entry point into thinking about disability relationally is so different. So, this is a long-winded segue into this question about tensions between parent groups and disabled activists. What are some of those tensions and some of the case studies that you address in your book? But we don't only want to focus on tensions. What are the examples of alignment that you want to highlight too that you found in your historical case studies between parents of people with disabilities and disabled activists?

**Allison Carey:** I mean there are different tensions, but when we look across the case studies there are some commonalities that have really come up already. So, we've talked about the medical model versus the social model, this idea of the medical model being trying to fix a person, really embed the person within medical interventions versus a much more empowered rights approach for a person with a disability. Another key tension is expertise and authority. Parents fought really hard to have authority over their families, authority over the decisions related to their children, and it's important to understand why they did that because in institutionalization their children were pulled away from them and often made wards of the state so parents actually lost their parental rights, and so parents fought hard to make sure that they were in charge of their children's lives, but then their children grow up and become perhaps disabled activists, and disability activists are looking to have authority over disability policy. They are looking to be the people at the table and to have the voices and to be the narrators of their own stories. Sometimes parents don't recognize that. Sometimes parents don't recognize that there's actually a conflict of interest between what is good for a family and what is good for the person with a disability. And so, striving for normalization or saying, well, our family needs you to do this, right? Our family needs you to be in a disability specific setting because then I can go to work, right? And that's a really valid parent concern. Once somebody is an adult or even as a child, right? Don't they have a right to be in an inclusive setting? Don't they have a right to be making some of those decisions themselves? So, authority and power are a huge tension and integration and segregation or what parents call specialized services. This is a huge one. Most of the major disability rights organizations led by people with disabilities fight for maximal inclusion. And parents often still believe, and not all parents, again, very, very diverse, but some of the parents groups are still fighting for there to be involuntary commitment for people with mental illness, for there to be separate schooling, for there to be segregated day programming, and so parents still often imagine that segregated services are safer and more effective and the research does not bear that out, but that is it's really really hard to overcome that myth and even the dream that parents have that

somewhere there's this place where their kid is going to be really accepted and it's a world built for them and those separate worlds actually tend to be devalued, right, they tend to have low expectations.

**Pamela Block:** Or are unsafe.

**Allison Carey:** Yes, often they are unsafe. Also, parents are facing the fact that integrated and inclusive settings often aren't that inclusive either. And so, they're looking for an alternative, they're trying to make these decisions. That's another area of clear tension is how much parents will often support specialized or segregated services versus the real demand to build inclusive structures. Pam, why don't you talk about alliance and some of the more positive.

**Pamela Block:** Despite these very real tensions, we also found that in many ways this notion of allies and obstacles is, as I mentioned at the very beginning, a bit of a false binary because sometimes it's the parents who are disabled, sometimes both the parent and the children are disabled. Sometimes we're talking about multi-generational families that are engaged in really complex mutual care relationships that fall into very different approaches than are typically represented. And this is especially true when you're talking about people coming from intersectional identities in different communities, different ethnic or racial communities. So, aside from that, there's also the policy aspect where these movements have been, and Richard can speak to this very well, how the social movements run by disabled people and those run by parents, where have they been able to work together very effectively to pass significant legislation and enact different policy changes on different local and regional and national levels. But at the same time, we really have to think differently about how and why these different categories engage and also how experiences like parents, even their notion and their understandings of disability change over time. The parent of a newborn has a very different understanding of a new diagnosis versus somebody who has a 10-year-old or a 20-year-old or a 50-year-old child. And when they have a 50-year-old child and they themselves are in their 70s and 80s, their own embodied experience of impairment and disability has changed, and the balance in the family of who is disabled and who is more disabled or whatever, you know, might change over time as well.

**Richard Scotch:** Let me just make a couple of comments about alignment following up on what Pam said. And I think this gets into particularly some of these disability justice issues. So, the whole debate a few years ago over whether to keep or get rid of the Affordable Care Act was an incredible example of alignment because the parents and the children all wanted access to health care for anyone, but particularly for low-income people and people with disabilities, and they wanted the exclusion of pre-existing conditions to be struck down. The sort of rights for basic income, whether it's minimum wage, or whether it's disability benefits, or whether it's social security benefits, people agree about that. There are all kinds of aspects that are not maybe disability specific policies, but are basic kind of social justice policies, where there's a lot of agreement. Most disability activists would prioritize inclusion over prevention, but I don't know if there are many, perhaps there are some in the deaf community or in the neurodiverse community, but by and large people support biomedical research to prevent some of these conditions. So, I think there are a lot of shared areas and particularly as some of the programming that has come under attack by the increasingly conservative legislative bodies, you know, those coalitions persist and not just within the disability community, but within other marginalized populations. So those are important issues and often that will motivate parents as well as what kind of placement their child gets or what kind of specific services their child gets. I think those are examples of alignment and those will continue as we fight over what a just society should be providing to its members.

**Caroline Lieffers:** Thank you so much to all three of you. That was really, really interesting. And what I especially appreciated about these responses was just the

nuance and the complexity of this. I think that's something that runs through your whole book, right? There's a lot of nuance and complexity. And I wondered to what extent the interviews that you conducted as researchers sort of helped you tease out some of that nuance and complexity. I'm always fascinated when scholars are able to find people to interview who are, you know, eager to talk to them. Whether anything like surprised you in the process of doing interviews, what were you hoping to achieve? Why use interviews as a part of your methodology? Feel free to just talk about that in general.

**Allison Carey:** Several of the interviews began as somewhat of a different project. I actually began by interviewing parents who were supporting segregated services, who wanted to keep specialized day programs and even institutions still open, and I wanted to hear their view of rights and disability rights and how they were positioning themselves. So, for me, those were really interesting because you can hear from those parents that they are struggling even today to find appropriate services, right? They are struggling. Many of their kids are now adults and they are aging themselves. Their ability to keep caring was limited. We talk about community inclusion, but our service system is so haphazard, it's so unequal. And so, they were really looking for security for their children or adult offspring. They were looking for good educational programs and they felt still like they had really constrained choices. So, there are ways that I really sympathize with that position, although for me politically, I feel like it is very important to put our money and resources into building inclusive programming, community based programming, right? And so that's where the interviews actually began.

Then we started seeking out more parents who were fighting for inclusion and parents who came from different backgrounds. I think for me, one of the most interesting things was that parents will often say that when the child or adult offspring is more disabled, that's when you need kind of these more specialized segregated services. But we talked with parents with offspring that had severe disabilities and they had found ways to have community support to include their children to build meaningful lives. And so, I didn't see as close of a tie, right, this argument that people with severe disabilities need to be in segregated services. I don't think that that's true. On the other hand, I will also say that the parents who managed to build these meaningful, inclusive lives for offspring with severe disabilities, they were working really, really hard at it. They were often opening up bakeries so that their kid had a place to work. They were identifying the caregivers and managing the caregivers. And they were worried. Even they were worried about what was going to happen when they passed away.

**Caroline Lieffers:** That's really important. And actually, this leads to the next question that I was going to ask, which also circles back to something that you mentioned a couple of questions ago when you were talking about rights, right? These sort of rights-based approaches. One of the things that's so brilliant about your book is the way that you talk about how the rights can sometimes be in tension with one another, and I can see that actually coming through in this response that you just gave as well, where a parent might feel, well, I have a right to security. I have a right to not have to worry about needing to be a caregiver for the next 50 years of my life and what that might look like. And yet, of course, the person with a disability also has rights. And so there can be these tensions that emerge. And I was wondering if you wanted to just talk us through any particular examples that you think are really salient here. And then I think the follow-up question is, do we need to resolve these tensions? Is there even a way to do that? What would that look like? Or can we let them sit in tension? Your wisdom here would be really appreciated.

**Allison Carey:** Thanks, yes, I'll give you an example or two and see if other folks want to chime in. One of the examples that I think is most interesting: when we think about rights, they are framed in this very individualistic way, right? So, I have a right to something, but things like service delivery, healthcare, these are systems, and systems can't cater to everybody's choices, right? And so, it's very easy and my students say this

all the time, like parents should just have a choice whether they want their kid to be included or whether they want their kid to be in a specialized school, and they can just figure this out. But school systems with limited funding often need to make decisions about if they are going to support a special school, and if they're going to support a special school then they are channeling the professionals there, they're channeling special educators there, and then they are often gutting those inclusive programs in their district schools. And so, it's not really a choice anymore, right? You have a choice between a specialized school where the experts are and the programs are, or you have a choice between inclusion without the experts, without the assistive technology. Then what are parents going to choose? And it looks like parents are choosing the segregation, but the system has been set up that way. And so, my choice affects your choice. I think it's important to acknowledge that then the education itself, this is one of the reasons why just this idea of least restrictive environment hasn't played out. IDEA was passed in 1975.

We still see kids with intellectual disabilities in particular going into special education, into segregated programming, and it's largely, again, because of the structure of the educational systems and the district and the funding. So many parents rely on this idea of "I have a choice and it's my right to choose." I think that's a really problematic thing. You also then get into this idea of who's choosing, right? Again, going right back to this tension. So, if as a parent, you're claiming a parental right to medical treatment, if that medical treatment is something like sterilization, cochlear implants, right, and that you are making lifelong decisions for somebody. And so, you know, along the way we did often decide that sterilization was not appropriate, but this is still debated. There are still instances of parents deciding to sterilize, even youth with disabilities without the person being really involved in the consent. Then you brought up this issue of parents feeling like they have rights, right? So, parents wanting to choose an institution or a setting that maybe isn't as conducive for the person to flourish, because they are looking to have their own life at some point. My thing isn't to blame parents. My thing is to think about the constraints the parents are facing, recognize those constraints head on and say, we are not providing the funding, the infrastructure for people to be successful in the community. Parents have been given, have been told, right, we're going to deinstitutionalize and hey, you figure this out for your kid. You ensure that they have the caregivers. You take care of this for decades and decades. And then again, what happens when the parents die? So, this is a real conundrum for parents, and the whole idea of rights just doesn't help us get at. I do think that we need to—I think the idea of disability rights is super important, right? We need to recognize that people have rights, that they're empowered. But I do also think that these systems of like universal healthcare, of ensuring that people have affordable housing, of ensuring that people can get the level of services that they need as they need them without being pushed into segregated services. And some people will want to be in group homes and that's great. And some people will want to go to a day program, right? And that's great. But if that's our only option, then that's not acceptable.

**Caroline Lieffers:** Yeah, I think that's really powerful, and what you're saying about rights being an inadequate framework for this is crucial. I so appreciate that. Yeah, thank you.

**Kelsey Henry:** So, in this conversation that we've had about tension and alignment, we're talking about a really wide cast of characters when it comes to your historical actors. You write about histories that bring in people with competing interests, people with aligned interests around the subject of parenting and disability and disability rights and disability justice. There are a lot of actors, which brings up questions about audience. So, for you all thinking about the way that your book has been received, I'd love to hear a little bit more about the different audiences that your book has appealed to, both in terms of when you were conceptualizing the book itself, who did you imagine your audiences to be? And now that the book is out there in the world, how has it been

received by your intended or imagined audiences? And have you found audiences for your work that you weren't expecting?

**Allison Carey:** I've been really pleased by the reception it's received in academic audiences. I think we wanted to make it accessible, but it is still primarily an academic book. It did win an award from the American Sociological Association and from the North Central Sociological Society. And so that was really exciting. I think as Richard had said, there was so little scholarship on parents and the scholarship was often really contained to a single disability or a single parents group and so providing a more sweeping discussion of parents, a more diverse discussion of parents, I think has been received really well. For parents, I think many parents appreciate the book. I think some have pushed back a little bit on what they see as criticisms of parent activism or ideas that parents should prioritize alliances with organizations led by people with disabilities. So, I've been really happy with our conversations with parents but there are often questions and some concerns raised.

And then for me, I think that the most important part is when activists with disabilities read the work. And I think it speaks to many activists with disabilities who often have an experience where, for some of them, their parents have been their greatest allies. Their parents are the ones who fought for them to be in school, who provided their transportation, who helped them type papers, right? And often their parents are the ones who taught them to be activists. But then there are also people who grew up in families where medicalization was prioritized, where the activism was seen as a very different kind of activism, right? It was activism to be included as if you didn't have a disability. And so, I think people with disabilities can see their different experiences represented in the diverse stories going on in our book.

**Caroline Lieffers:** Thank you so much for that. This is maybe a related question, which is, where are you hoping this conversation goes next? Are you hoping for particular changes? I mean, Allison, you alluded earlier to some important ways we need to reconsider the systems, right, that are behind a lot of this. Do you want more research to happen in this field? What are you hoping people take away from this book?

**Richard Scotch:** Well, we hope a lot of people read the book. We have another edited book in the works that Pam can tell us about or Allison can tell us about. But I think a lot of the—just going back to your previous question—people who've really sought us out have been the parent groups. I think the disability studies folks have, I don't know about the disability history folks, but the disability studies folks have been very interested. And I think a lot of them have been pleased with how the book frames some of these issues. I think the parents really wanted to know more, and maybe some of them aren't entirely satisfied with what they've read, but, you know, they at least are getting acknowledged, which is something. I think what we would like to happen in terms of practical change is that some of the parent groups pay a lot more attention to what the other disability activists are talking about and listen to that because I think in some cases they do listen and in other cases they don't even think to listen. Or in some cases they reject what they're hearing. So, I think having that kind of more constructive engagement between disability activists and parent activists, you know, I think that would be a great thing because I think there is a lot of room for improvement there. But it's unfortunate that because of all the resource constraints we are aware of in the world we live in now that people are faced with some of the choices that Allison referred to. I always like to go back to these focus groups that were held back around 2000 about the census and how the census question that tried to measure disability. And what came out of these focus groups from people with disabilities was that disabled people do things differently and often are very creative. Another colleague and I are working on a project interviewing political candidates with disabilities. And many of them talk about their disability as a resource, as something that has trained them to be creative problem solvers, to think in new ways about how to accomplish things. So, I think the dialogue that we hope for

would perhaps lead to some ways of doing different things that aren't just this binary, well, segregation versus integration. That may be some blended possibility. But I think the other thing that we hope will happen is that people will read this other edited book that we're in the process of creating that includes a lot of different voices beyond the ones that we've addressed in this book.

**Pamela Block:** We really did try very hard to be as representative to as many voices as we could in the book, but we were just necessarily limited we couldn't cover every single disability experience, or every single racial and ethnic experience you know and not that we've and not that we've completely solved that problem with the new book, but we were able to expand these conversations and have the narratives being controlled by the people themselves most affected. So, we have activists and scholars and parents in conversation with each other or reflecting from these different positionings. I'm really very excited by the potentials of this. My most favorite experiences talking about the first book, the *Allies and Obstacles* book, was in settings where we were together with activists and parents and all of us kind of reflecting and processing together. And so, I feel like that's what we've asked our chapter authors to do and what they've just sort of spontaneously done and now we're in the process of—I was telling them I was like, you're already in conversation with each other. We met all together for the first time today. And they were like, we're not really sure how that could be possibly true. But by the end of the meeting, they're like, oh, OK. You know, after everyone sort of talked about their chapters and they could see the connections, the growing up childhood experiences, the interactions between the choices that parents made regarding technology and other kinds of interventions on children and the kinds of advocacy that parents make versus, you know, that children themselves were supported by their parents to make, or made in spite of their parents, and the kinds of legacies of coming from different racial and ethnic communities that understand disability in completely different ways and respond to disability in completely different ways, both positive and less supportive, and how that has impacted them as emerging adults and structured their activism. And so, we're very excited about that.

And for me personally, I have another project based in Canada, looking at sibling care relationships. We're interviewing pairs of siblings together and learning about the way that they support each other. And we're really talking about older siblings, in many cases, siblings whose parents have passed on. So that the sibling care relationships are our primary care relationships in people's lives, where they might be living together, and in Canada, where there are different legal supports and structural supports. I mean, we haven't explicitly said it, but we've implicitly made it clear that most of our cases are based in the United States, right? And there are some real differences just between Canada and the U.S. In terms of the kinds of supports and what is considered to be the rights of people and what are considered to be the obligations of people and of families, right? It plays out very, very differently and I'm very aware of this living in Canada, interviewing all of these families and these sibling pairs and, you know, me myself being a part of a sibling pair where she's receiving her services in the US and I can really see the stark contrasts, right? So, I talk a little bit in the new book, I write a chapter where I'm talking a little bit about a sibling activism, but that's really largely untapped in the work that the three of us have done together. But it's something that I'm kind of developing on my own.

**Caroline Lieffers:** That's so exciting, and I'm really thrilled to hear about the attention being paid to Canada as well as a fellow Canadian.

**Kelsey Henry:** Are there any last thoughts that anyone has or questions from you all for each other or for us? Anything that's still lingering towards the end of the conversation?

**Pamela Block:** I believe we have a discount code, by the way. If people are interested in purchasing the book, there's a discount code. I can't remember what the discount

code is, but we will get it to you and then you can include it.

**Kelsey Henry** We can, we would love to include it. Thank you so much to Allison and Pam and Richard for joining us today. We're so excited to share this episode with our listeners. And we hope that you all have a wonderful rest of your evenings, afternoons, wherever you are in the world. Thank you so much.

**Allison Carey:** Thank you for having us. Thank you.

**Richard Scotch:** It's been an interesting talk.

**Caroline Lieffers** Thanks to everyone out there for listening or reading the transcript. Please join us again next time. Bye-bye.