Disability History Association Podcast
Interview with Susan Burch
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Kelsey Henry: Hello and welcome to another episode of the Disability History Association Podcast. I’m Kelsey Henry.

Caroline Lieffers: And I’m Caroline Lieffers.

Kelsey: And it's our great pleasure today to be in conversation with Dr. Susan Burch. Susan is a professor of American Studies at Middlebury College and her primary research and teaching interests are vast and they include histories of disability, deafness, madness, race, ethnicity, gender, sexuality, and Indigeneity. Susan, thank you so much for joining us today. We're really, really excited to talk with you.

Susan Burch: Thank you for letting me join you. What a treat.

Caroline: Well it’s a real treat to have you. I know you wanted to start off with a few words of thanks, so please go ahead.

Susan: Thank you. I’m joining you today for this interview on the ancestral and unceded occupied territory of Abenaki nation. And as a grateful guest on these lands, I want to express explicitly my appreciation for Abenaki ancestors and elders past, present, and future, and also very deep gratitude to all of the people who are named and unnamed in this podcast who helped make my work and my world possible. So thank you. And thank you.

Caroline: Wonderful. Thank you so much.

We’re going to start with a question that we ask many of our guests, which is, can you just tell us a little bit about your journey to becoming a disability historian?

Susan: It's a story with lots of different beginnings. So I’ll just pick one that is still a truth for me, which is that I was drawn to deaf cultural history first, from long ago roots in childhood through graduate school and imagined that I would dwell in the realm of deaf cultural studies for the remainder of my career.

And it has continued to be an important feature of it. But thanks to colleagues in disability studies and disability history who recruited me to the Society for Disability Studies in the mid-1990s, I met more people who were meant to be my people and more homes that were meant to be my homes. And so it was through friendship networks and shared interest in experiences of what we would now say critical ableism and interlocking systems of power and privilege that made it clear that my world was more large and interlocking than I had imagined.

I'm grateful for the teaching and the patience of others who continue to expand that for me. I will also note that in the early 2000s wonderful mentors and colleagues in disability history got together and pushed for what brings us together today, which is Disability History Association. And in part building this Association with, with so many wonderful folks has been a real highlight in my life and my career.
So it's, it's not quite full circle, but a beautiful spiral to get to come back and join you today for the podcast.

**Kelsey:** I love the way that you were narrating how your entry point into disability studies and disability history was really like foundationally because of people that you encountered and communities that you found. I think that we all have different entry points into what we study, and it's really beautiful that you found yours through people in community that felt like home to you. Yeah.

**Susan:** I think a melody in my life has been that the relationships with others imbue my world with meaning and fill it with the stories that guide me. I hope that that shows up in the teaching and the scholarship that I do as well.

**Kelsey:** It really does, that focus on relation and kinship. Absolutely. So we'd love to hear a little bit more about your current or your most recent book project, *Committed*. And this is a book that foregrounds the lived experiences of people who were incarcerated at the Canton Asylum in South Dakota, right?

**Susan:** Yes.

**Kelsey:** A federal psychiatric institute that detained Native Americans. And you also focus on the lasting impact of, of this history of incarceration and institutionalization on families and descendants over time. I'm wondering if you can say a little bit more about what it meant for you or what it really looked like to approach these stories from the perspective of disability history. Because not everyone would necessarily tell them through that vantage point. And why did this feel like an important framework for the stories that you encountered?

**Susan:** Thank you. So, one of the pathways into this work for me, which was not an expected one, was in collaboration with Katherine Ott at the Smithsonian National Museum of American History. When we were working on a collaborative artifact-based exhibit called Every Body. And I was really drawn to look for disability histories that hadn't already been told and that didn't replicate already dominant structures that we see in American society and then in disability history.

And by that I meant I wanted to look for stories of Black, Indigenous, people of color who were disabled, disability lived experiences that have not been in the front of most of the scholarship and the stories that we tell. And with Katherine's support was digging around in the databases of the Smithsonian and came across a 1903 *New York Times* article that announced the opening of the US Government Insane Asylum for Indians in Canton, South Dakota.

And I have to confess, I was really disoriented by that article. I had a background in studying institutions and institutionalized people, which is not to say that I understand or remember all institutional histories or histories of institutions, but had enough familiarity to know that there was a federal psychiatric facility in Washington, DC, where we were living and working, but had not known of any others.

And to see this announcement of an institution specifically designed to contain American Indians was, um, rattling for me. And Katherine urged me to keep looking, to figure out 'what is this story.' So originally I thought it would be a component merely of the exhibit and it grew, and it grew, and it grew. And eventually I thought, perhaps this might be an article that I pursue, which pushed me to look into the National Archives, which had what
turned out to be thousands and thousands of pages about the people who were detained at Canton and about the facility generally.

And from there, it became abundantly clear—and I credit Katherine Ott with nudging me to embrace it as its own book project. And back to the point about relationships guiding the path, I had wonderful colleagues around me giving feedback and noting that the story was important and needed to be told. And after spending significant time in the archives, I began to wonder, and this comes from roots in disability history-- what are the other stories of these people beyond these pathological, racist, sexist descriptions of these men, women, children, elders? So I wanted to know: to whom did they belong? Who claimed them? Who did they claim? What else can we learn about these people?

And that pushed me to do genealogical research. Unfortunately, genealogical research with databases like Ancestry.com themselves reflect white settler norms. And so I was able to find many people who were related in particular ways to the people detained at Canton, but so many relatives I couldn't find through that particular access point. But what became this magical opening was collecting the digital materials from all of these different archives, building a database, and then writing to Tribal Historic Preservation Offices and writing to individuals who seemed to be related to the people I was learning about. And introducing myself, expressing that I was interested in doing this project that didn't have full shape or form yet, but that these materials belonged to them. And if they wanted free copies, I was happy to share them, no strings attached. And if anyone was willing to talk with me about families, I would welcome it. And incredibly, many people answered, and it was through these interpersonal relationships, some of which have become beautiful friendships, others that have been terrific collaborative efforts (but not friendships) opened up worlds for me that continue to help me unlearn my training as an historian and fully changed the entire trajectory of the project.

Kelsey: Everything that you’re saying is making me think about sort of a frustration that I have with the ways that institutional histories are often written. Which, and I feel like this is a shift that I’ve been noticing more often, of really asking questions of the people beyond their patienthood, and inquiring about-- I love that question that you asked about who did these people belong to, who recognized them, who claimed them as kin.

And it really is a kind of care work to recover those genealogies of relationality and asking questions about who were these patients beyond, or who were these people beyond patienthood, I think is so critical.

Susan: I’m nodding up and down in, in affirmation of that. I think one of the significant learnings for me, which comes through relationship with others (I write about briefly in the book) was getting to know Pemina Yellow Bird, a terrific writer who’s from Three Affiliated Tribes (Mandan, Hidatsa, Arikara) and Pemina has done remarkable foundational work about Canton Asylum and the people detained there. And we’d been talking on the phone for many months and were thinking through different aspects of the story. And I had used the word "inmate" rather than "patient" as a particular intervention to counter Western biomedical frameworks that reduce people into this submissive medicalized entity. I wanted to draw out the ways that power and incarceration functioned. And Pemina wasn't having it. And she said, “Susan, I don't want you to talk about my people as inmates.” And that stopped me right in the moment. And I responded by saying, “I hear you. Okay, absolutely. We can take that out of the writing, but I cannot call them patient, as a disability historian, as a crip person, and as an activist, I can't do it.” And Pemina kind of nodded verbally. And she said, “how about calling them people?”
And that for me was this incredible gift to remind me, not as a checklist of methodology, but to keep coming back to the recognition that I'm writing about people. So much of the work that we do in disability history is about people's lived experiences. And I find it really helpful on a regular basis as I'm working with different materials to come back to saying “people.” So who else were they to other people? What other relations, what other names were they known by, would they have used for themselves? How can they be remembered beyond what the papers in this musty folder are telling me? So I'm eternally grateful to Pemina for, for that gift.

**Kelsey:** You're absolutely right that the language that we use invites certain questions and forecloses or shuts down others. And that shift that you're describing from patient or inmate to person, I think perfectly demonstrates the ways that, yeah, language welcomes different lines or like avenues for kind of more careful questions about historical subjects. Yeah.

I'm wondering if we can pivot a little bit more. You've shared the ways that this book is anchored within disability history and disability studies, but it's also primarily rooted in Native American Indigenous history and Indigenous studies. So I'm wondering, how did this combination influence your work and work in practice?

**Susan:** It has influenced it at every single register and every single draft and conversation, I would say. Part of what's important to me to recognize is that I came to this particular project identifying as a disability historian with no training or no background in Native American Indigenous studies and as a white settler, at this point living on ancestral lands of Abenaki Nation. And so learning into the field of Native American indigenous studies has propelled and increased the momentum of unlearning my training as an historian. By that I mean, as a disability historian, I came to the archival sources with skepticism about the diagnoses present there, with critical attention to the ways that power works within institutions, and a desire to push against those and to pay attention to ableism.

By learning into Native American Indigenous studies, and for me now, the overlaps of these two fields are amplified; it propelled me to start questioning at larger scale Western biomedicine as the framework to push against in the first place. And to recognize that there were multiple systems of medicine at play and multiple sovereign nations battling over self-determination, and that medicine and people and institutions were sites where these battles played out. And in ways that I used to think about the weaponization of Western medicine as a force, and I still see it as a force that appears across histories, placing it in a broader context where it is not the only force and paying attention to the ways that settler colonialism saturates this story and my understanding of disability itself -- to even call it disability when across different Indigenous systems of medicine that has not been the construction of judgment attached to the variations of bodyminds. So that very core feature is still churning for me, and a wider and more complex appreciation of kinship and the continuation of these forces and the continuation of efforts to maintain and grow self-determination that are not the same as what white disability history and studies has been teaching us.

And so I, what else to say? It continues to be a nourishment and a provocation for me to hold both fields together and not merely as contrast, and also to recognize that story, which is not unique to Native American history--the place of story, which I had not been trained to attend to-- has now become a fundamental feature of how I want to understand our past; how I want to share it in the present; and how I want to dream it into the future.

**Caroline:** Thank you so much for that answer, Susan, because your book features the stories of so many different people and also their kinship networks as their lives are shaped
by all sorts of forces: forced erasure, removal, confinement, surveillance, but also love and care and kinship and belonging. And I want to dwell a little bit on the fact that you selected one person, Elizabeth Alexis -- is it Faribault? Is that how you...?

Susan: Faribault.

Caroline: Faribault, yeah, as well as her kinship networks to kind of narratively bookend this book in many ways. Why did you choose Elizabeth Faribault as your kind of through line?

Susan: I'm smiling as I'm thinking through how to answer that there. At a very fundamental level I don't think I could have imagined this project without Elizabeth Faribault at the center of it. As a researcher looking through archival materials, her story surfaced very vividly early on in my work. Her story has appeared in other scholars’ works, but in a very different fashion. But it's a striking and searing and heartbreaking story in many ways. And so it has held me.

But it's the personal relationships and what engaging with relatives of Elizabeth Faribault continued to teach me and help me undiscipline myself that became a tribute, I guess, in a sense across the book. Which is to say, among the very first people that I met from that letter writing practice, introducing myself, was Faith O'Neil, who is the granddaughter of Elizabeth Faribault and the daughter of Cora Winona Faribault (who was born at Canton Asylum). And I still marvel that Faith O'Neil was willing to take a chance on me. If you'll let me digress a moment, I'll give you some backstory to it.

Faith O'Neil has been searching for her grandmother for decades now. She initially had been looking for her half-brother, David, when she learned who Elizabeth Faribault was or that Elizabeth Faribault was her ancestor. And so this opening in her own world sparked a whole path that has, has driven her, her life. So you can imagine her excitement when she found out that there were publications in the world about Canton Asylum, in which her grandmother figured. And according to Faith, she purchased a book that had been published and went leafing through it to find more information about her grandmother. And the work had replicated directly what Canton officials and staff members had said about Elizabeth Faribault, which is to say deeply racist, deeply sexist, pathological descriptions justifying her commitment to Canton Asylum and sustained detention at Canton Asylum. Literally blaming Elizabeth Faribault for giving birth to a child eleven years into her internment at Canton Asylum. It was incredibly wounding. It's still incredibly wounding for Faith O'Neil to have had that experience looking for scholarship and all the power culturally and otherwise that published materials carry.

That had happened not long before I knocked on her door with this paper letter. And so according to Faith, and she's given me permission to share this story out, she sat with that letter for a while, and I sat waiting also, but not knowing or expecting her or anyone else to respond to my flurries of letters. And then eventually she did call me. And we began a very slow and careful and tentative and increasingly interesting and vulnerable and vibrant ongoing collaboration, which has become a very dear friendship now.

And as we began to learn each other and learn into the story of her grandmother, the questions of where Elizabeth Faribault is buried, which still haunts Faith O'Neil, it still haunts me and continues to be part of the work of this book that is ongoing long after the book -- which is one of the things that Faith O'Neil has taught me, is that the research project that I thought would be a book, became a project much larger than the book. The book is one offshoot of lifework.
And so we're still looking. And I think that practice and the relationships and spending time together, traveling to South Dakota together, going to an honoring ceremony at the Asylum's former grounds for me, has changed me as an historian and a storyteller. And so the presence of Elizabeth Faribault is everywhere felt in my world also now. But it's also the continuation across the generations and the tenacity of Faith O'Neil and others whose ancestors were detained at Canton that reminds me that these stories are never done. They continue to unfold.

**Caroline:** Thanks, Susan. It’s really incredible to hear about your journey through this material, through these relationships, and then knowing that that journey is not over, right? And it is going to be continuing to shape who you are, your scholarship, and our larger communities, right? Which is, it’s incredible. I want to pick up on this thing we call microhistory, I guess, since about the seventies, right? That's been the term that historians have been using to talk about this very specific kind of approach to history. And it's one that I personally love. And I think you in your introduction talk about this book as being one of microhistories, right? It is in many ways a microhistory about this one institution, but also the microhistories of individual lives and families and kinship relations. And I have a few thoughts, I hope they'll turn into questions about microhistory. One is that microhistory, and I'm probably going to paraphrase this somewhat badly, but there's a wonderful historian who said that microhistory is about asking large questions in small places. And I would really love for you to expand on this a little bit and tell us about some of the large questions that you were able to get at through these small places.

And then I have a follow-up question as well, which is, do you think that this approach to telling history and the storytelling that often will go along with this approach can be kind of like a tool for decolonization or intergenerational healing? And maybe tool isn't even the right word, so I'll leave that open for you to meditate on.

**Susan:** So I think Chas Joyner, who's the brilliant scholar that gave us that phrase of using microhistories to explore large questions in small places and that particular framework. And that particular person is dear to me -- his daughter is Hannah Joyner, with whom I've collaborated for many years and who is one of my favorites. So it's, it's a wisdom that stays close by and resonates increasingly with this project in that, when I think about my training as an historian, so much of it was focused on theory and concepts and schools of thought, which are important sources of knowledge, utterly unconnected to embodied people in the world. And when I compare that to how I actually learned history as a young person, which was listening to my grandparents tell me about the places that were important to my family, where people lived and did things. And so my understanding of who I was and my place in the world was actually attached to family story. But my training as an historian went in a completely different direction. And I, to a certain degree, forgot my early training as an historian from my family.

And so this project returned to that combination. It's not the only project where that's been an invitation, but it's certainly blossomed in different directions and much more vibrantly, I think, if I was looking across the portfolio of my work. Which is to say that I am grateful to the colleagues and the mentors who teach us the big, important concepts. But for me, story is what gives all of it meaning, it breathes the life into it. And it pulls us into action. When I think about collaborations with other activists and with family members in this project, no one's waving Foucault when they're talking about justice. No, one's talking about theory when thinking about the ramifications of having kin stolen from them and kept from them and living with absent presence and with present absence. And so for me, story has gone
from an illustrating example of an argument, which is what I was trained to do with story, to the very center of the work itself.

And in the book project *Committed*, friends who were very patient and read oh-so-many drafts of this work will attest that earlier drafts were much more academic. There were many, many more explicit references to other scholars. Those were the people I was having conversations with in early drafts of this book as I was thinking through the ideas and using the examples of families, life experiences, to fill out those ideas. It was much more shrill, which, much less human, and it did a disservice to kinship itself. And it took a network of people who were holding me and holding me accountable to get to a realization that I had to push back against my own training. And I had to actually listen to these family members who were teaching me the whole time of what mattered and to let that be the center and to build around it from there. And so the book literally shapeshifted over the twelve years from early archives and Smithsonian research to out-in-the-world book.

And I'm grateful for the patience of others who kept telling me the stories as a way of modeling rather than directing, and finally getting to listen to it more thoughtfully has, has nourished me. I hope it's nourished the book.

**Caroline:** Do you feel that your, how do I put this? I guess like this book is, is not just about stories, of course. It's also about these massive forces, like settler colonialism and racism and ableism and sexism. And did you find it difficult to kind of do that work of taking the story and then translating it into an understanding of these larger forces? Or did that feel so organic as you are exploring people's lives that you're like, how can I not be also talking about these things, right?

**Susan:** I wish I could say it was completely evident to me from the start and that I had it all figured out. This book took a long time because it took a long time for me to get more clarity on what needed to be through-lines in it, what needed to be noted and how, in a way. I think for me, part of the challenge has been to hold the dignity and personhood of the people that I'm learning about and sharing their stories with their consent to do so, and noting the horrific and ongoing material consequences of settler colonialism, of racism, of misogyny, of capitalism, of the weaponization of Western biomedicine. And to take very seriously Eve Tuck, who is a brilliant scholar in Native American Indigenous studies, who cautions those of us who share interest in this field and share interest in Native sovereignty, not to collapse the story and the representation of Native people as merely victims.

And it's a lesson that I think disability historians who aren't necessarily studying Indigenous histories, but who should, should also take very seriously about 'how do we hold, how do we make transparent how these forces land in everyday lives,' at the same time recognizing the complexity of people's everyday lives?

So to come back around to ‘how do we contend with these forces?’ For me at the beginning, attention to ableism was always present, but I hadn't understood it as settler ableism. And I'm, I'm nodding at you Caroline in part because our conversations as I was working on this book and the work you are doing that is so important and paying attention to how we think about ableism as an historic force. And I'm so grateful to colleagues in disability studies who draw our attention to ableism And as an historian, I am so grumpy trousers about what is often the absence of historical context and the contingencies and the specifics of placetime, and its malleability.

But to note that if, if we take seriously the brilliance of our colleagues and comrades in critical race and ethnic studies and gender and sexuality studies among other important
realms, that these categories mean different things at different times (because of course they do) they’re birthed from these systems that also shapeshift over time place. And I’m early in my wrestling match with thinking about ableism across histories. And so many questions stay with me that I look forward to the two of you and others who are, who are nourishing our field to help us think more carefully about ableism and not merely to gloss with that word, but to recognize all the different ways it takes form.

It struck me that in thinking about large forces, ableism is an, is a propelling force in buttressing settler colonialism. It’s an essential component of how racism functions in the United States and how sexism functions in the United States and the ways that they interlock, but are not interchangeable was something that, that showed up at every turn as I listened to the families. So in the back of my mind, I’m thinking of things like how these forces are interlocking, but the stories weren’t saying that explicitly. And so finding the bridges between the everyday ways that that landed and all of that broader context that wrapped around them has been part of this work.

Caroline: Yeah, thank you so much for that answer, Susan and yeah, I completely want to sort of echo what you're saying about Eve Tuck’s warning against just doing this damage-centered research, right? And how that can simply just repeat some of the same sorts of mentalities and harms of settler colonialism. So, absolutely. And I also just want to, yeah, again, stress how valuable and precious this thing is that you're talking about, which is the kind of calling of doing history. Which is not just the province of professional historians, right?

Susan: Yes!

Caroline: The vocation that so many people are carrying with them in their lives to do history and to know history and to build those relationships that transcend time. And yeah, as you rightly are talking about in forming these relationships with folks, this is not just the professional historian's work, but indeed, actually, so much of it is grounded, you know, within communities and families. And it’s important for us to recognize that.

Susan: I’m nodding up and down and thinking about how many iterations of conversations were trying to find out the answer to something meant calling somebody's auntie or checking in with one of the people that I collaborate with directly. And they are calling the other family members to find out. And all of the things that at least an historian like I am, would never, ever, ever know without the assistance and the willingness of family members to share out and also their wisdom to share out ‘what has it meant for others to know?’ I think part of the importance of the work that we do as disability historians is to pay very close attention to the lesson that not all knowledge is meant to be known by all people at all times. And that goes against my training as an historian, which emphasize that if a material is in an archive, I have full right to use it and to use it hopefully in an ethical manner—whatever that meant— but to use it. And being engaged with Native activists as well as family members has brought me a very different understanding of accountability as a scholar and of the edges to access, and how we can use the knowledge that we have and the quirky skills that we've cultivated to hopefully support the kind of world that we want to live in now and grow more into the future. And that I find riveting, so energizing. I had never imagined that as an historian, I would actually make some kind of difference. I’m not suggesting that I’m making a difference much, but, but to be able to use research skills in support of Native sovereignty, for example, in support of individual families, seeking answers that they should have, and to be able to, to grow work that is far beyond me as a person is a wonderful gift. I highly recommend it.
Kelsey: I know that we have a couple of questions that we would love to talk through with you about access and accountability that I think speaks to what you were, what you were addressing about, sometimes you have to resist your training as a historian to be accountable to the communities in which you're engaging and to produce truly accessible historical scholarship.

But I actually, I want to weave backwards, towards something that you said that I just thought was really, really fascinating about citation. Like you mentioned that there was an earlier version, an earlier draft of your book that was a lot more scholarly or academic, in the sense that you were probably including the names of more academics in text instead of in footnotes. And I've had so many conversations with other academics about citational politics and citation practice. And I haven't thought about it before as a way of signaling community and accountability. And as historians, like, working in academia, I think there's a tendency to prioritize the community of academics over the community of your social actors, the folks who you're speaking to ethnographically or in oral histories. I don't know if this is a question or more of just what you were saying got me thinking about citation as community building, as a form of care, as a kind of accountability. And how, when you shift, shift your citational practice towards, the people that I'm citing our aunties, instead of foregrounding the names of academics in your text, it does, I think, change, change the text completely, like, who it's, who it's geared towards, who it's accessible to and does important work around reframing who's an, an authoritative knowledge producer, who are the knowers that we're turning to, in addition to community building. So just thank you for that. That was a really, really fascinating.

Susan: That's exactly it, Kelsey. What, what a gorgeous way of conveying it. Thank you for putting it together in a way I don't think I could have done so elegantly, but I think that's exactly the point. I think one of the things that I, I am glad for with how Committed came out in the end is that the body of the book, the story narrative part is, is not large. More than half of the book is the footnotes, or the endnotes, I guess. And that was an intentional intervention, as was what you were just describing of citing in the body of the book: mostly relatives, mostly the people who taught me the stories themselves. And one of the frustrations I have had as an historian anchored both in disability history and in Native American history is the absence of citations that get us to the sources to help us do our work. It's difficult enough to work in disability history with the erasure of our presence in the archives and in the research guides, and the complexities around terminology. That choreography is already complicated. But many works that I have found that intersect with Canton Asylum, for example, and broader histories, simply don't have endnotes or the endnotes are really vague. And to my mind, if we're going to have citations–and I think they're really useful–they need to be usable citations.

And a dear colleague in deaf and disability history, Bobby Buchanan, who is one of the folks who kind of held and held accountable across this whole book process, sat down with me one day and said, ‘Susan, are you writing for your dissertation committee? Or are you writing for family members who aren't born yet? Which is it?’ And I was at a crossroad with the book where that was exactly the question to ask me. And we are dear friends. It was a totally appropriate question. And it helped me pivot out of a trajectory that, that was more oriented towards other scholars, which is also an act of expropriation, of taking up someone's stories, but for purposes that are not empowering or liberating for the people who had those stories, who've made those stories possible. And so I was doggedly determined to fill this book with as specific a set of endnotes as possible for the family members, past, present, and future, and strenuously hope that it will be received as, as an enthusiastic invitation for others to find the other stories that I didn't include in this book, or
to add and change and encounter the ones that I put forth. Because this book isn't the end
of the story.

**Kelsey:** You worked with a really wide array of materials when you were doing research for
*Committed* and these included historical records that reflected the viewpoints of Western
medical doctors, US government officials, so among those records, I know that you work
with asylum annual reports, medical files, BIA (Bureau of Indian Affairs) correspondences,
but you also worked with more intimate familial archives. Like I know I mentioned, or we've
been talking about, oral history interviews and the families that you encountered, material
objects that you found through families. We love talking about archives and just our
primary sources on this podcast and nerding out about them, and asking that question
about what stories do these different sources invite, and which stories do they foreclose.
And why did it feel important to draw on such a wide range of sources in the telling of this
history?

**Susan:** Thank you for the invitation to go past the dusty papers. I think that haunting
question of 'who's not here and why, and who are these people beyond these medicalized,
narrow parameters’ insisted that I go literally outside of state and national archives to
understand the context, which turned out to be, understand the whole point of the work. If I
can dwell on a material object for a moment, as an illustration of the awesomeness of
material culture and the importance of expanding, at least for me, expanding the very
notion of what constitutes an archive. I think a lot about the quilt that’s on the cover of the
book, which is the Jensen family quilt (Prairie Band Potawatomi family). And the backstory
to that quilt is that O-Zoush-Quah, who is medicine, was incarcerated at Canton for
decades; and her children, like many relatives of people detained at Canton, fought
tenaciously to get her discharged and brought home. And like most family members, they
were denied the return of their loved one in their lifetime.

O-Zoush-Quah was an incredible artist. She did absolutely stunning beadwork that family
members generously showed me pictures of and showed me some portions of. Her
meticulous attention to color and texture, the flowers that she would build in beaded form
are just breathtaking. She also was a really talented quilter. And what, what showed up late
in the book process, but had been sitting there kind of the whole time waiting for the
invitation to join the conversation, was that her family has some of her material objects and
are searching for others, which is also a common story in Native American history. Artifacts
have been stolen from this family to be quite direct. So one of the questions were: where
are these artifacts? How do we find them? Can we find them? Which continues to be a
project, past the book.

But while O-Zoush-Quah was detained at Canton, her daughters insisted that she be given
piecework fabric so that she could quilt, which we understand, her relatives understand was
an act of care: to give her something to do with her talents and to help pass the time that
was endless. They didn't know whether she would get out. She didn't know whether or
when she would get out. And so the quilt pieces became a way of enacting kinship in
material form. So O-Zoush-Quah was taking these pieces of calico and stitching them
together in these circular plates that are, that follow a design called Grandmother's
Sunburst, which is just so perfect. And one of her younger daughters on the outside in
Kansas was also making sunburst designs from similar fabric. So this quilt is growing in
tandem in two different places. The pieces that O-Zoush-Quah made were eventually sent
to her daughter who collected and, and held them, guarded them. We think, in part, waiting
for her mother's return, which did not happen in her mother's lifetime.
The daughter kept these fabric pieces in her attic for more decades. And over generations, that stash of fabric got passed down to another generation and another, and eventually Jack Jensen, who's the great-grandson of O-Zoush-Quah, the grandson of the daughter who had held onto them, received these quilt pieces. That was in 2017. So this book was well underway. We had been interacting quite a lot by that point, and talking about the ways that my working on this book and collaborating with Jack had ripped open new worlds for Jack. And so recognizing that this kind of historical work is not neutral and it's not always only positive either. It was disruptive, it was traumatizing.

And thankfully in this instance, it opened up space for massive healing across generations, past and into the future. So Jack and I had been in regular conversations about O-Zoush-Quah and wondering about what her experiences were like. And then Jack receives this pile of fabric, which he didn't know what it was. And he gave it to a friend who's a quilter, thinking it might be useful. And she opened it up and realized this is actually a preassembled quilt. It's an already created archive. And called him back over to her house. And then when he recognized that his family members' names were stitched all around these plates; his grandmother, and great-grandmother had been sewing themselves in their kin into this quilt, to hold this family together in fabric form. He realized that it was the moment to assemble the quilt. And so he had his friend put it together. And in 2019, just as I had finished the full manuscript and sent it off to the press, I flew out to Texas to meet up with Jack Jensen and family members and dear ones to celebrate the arrival of the quilt. And so there was a ceremony to welcome this family member into the fold, as it were.

So I think about all that quilt continues to teach me about the artistry that is conveyed across generations. Of the different ways we practice kinship that are far beyond heredity [laughing] or, or even the names that we use for one another. And the different ways we wrap one another in kinship. And that this quilt is an archive. It is also medicine. It is a beloved member of this family and it holds together O-Zoush-Quah and all of her generation and before, and all of the generations that are to come for this family are also held in this quilt. I can't imagine any folder from the BIA in the National Archives [laughing] holding that level and depth and vitality of lived history. Although I still intend to go back to the National Archives and dig around the dusty papers. But if we're going to take seriously history as a lived experience and people as bodyminded presence, we have to go beyond the page and listen to the stories that are elsewhere.

**Caroline:** Yeah. I'd love to ask you more about that because this, what you're saying about this quilt brings up some essential issues about what consent looks like when you are dealing with people's stories. And what it means to have a record from a person who has in a way documented themselves, stitched themselves into the fabric of history versus somebody who was just reported on, right, by somebody else. And then that folder is dumped in an archive and someone comes across it a hundred years later, right.

And many of the tools that we are given as historians or instructed to use as historians, rules and ethical responsibilities and so forth about privacy measures and when it is and isn't okay to have access to a particular medical record are based on these very, sort of [laughing], what's the word depersonalize calculations about records being 50 years old or 50 years past the person's death or something like that, that are such a poor fit for the kinds of relationships that you're talking about. And also really fail to consider the power structures that generated those records in the first place and their storage, right? And so I wonder if you can talk a little bit more about the sort of ethical conversation that you were having with yourself, and also with these many people with whom you formed relationships, as you were working with some of these archival sources and the decisions that you were making about privacy and what to reveal and what not to reveal and, sort of, you're sort of
building an ethic perhaps as you were working through this, right? We’d love to hear your thoughts on that.

**Susan:** Thank you for that one. It's a set of questions that continue to propel me on a daily basis. So I consider this ‘in process.’ I haven't, I can't imagine that I will arrive at a place where I can announce “I've got it.” I think like justice work generally, it's process and it's relational, which is to say, for me, I wanted consent to be legible across this book. I have deep concerns about a tendency in, we'll call it higher education, to talk about talking about things, and to invoke terminology, but not to operationalize the words or the values. And so I wanted as much as I could imagine being possible, and it became many different practices, some of which I would want to use again, and others, perhaps not. But to make it, to anchor this in concrete ways.

I did research on many, many more families than appear in the book. But if I couldn't find relatives who claimed these people, I did not put them in the main part of the book. And some of those stories sit nearby and I commiserate with them on a regular basis and wait. Because I didn't want to create a project without relatives at least knowing that I was doing it.

It also meant that along the way, once I felt I had decent enough drafts, to offer the drafts to the family members, with what I hope were clear explanations that no one is responsible to edit my work—I’m fully responsible for all the errors I’ve made in the work that I do—but I wanted them to have the opportunity, as you have afforded me, to look back on what we generate together and to have time-space to decide what is appropriate to share in a larger public realm.

And it meant that at different junctures, ongoing conversations with family members shifted directions also. At different points, family members were excited about some of the stories and then later changed their minds. Or some family members wanted the stories and others were unsure. And I defaulted to any component that was going to cause anxiety or harm was not going to go into this book. The book did not need that. And in fact, it needed to not move in that direction of coercion against any of the family members whose generosity made the book possible in the first place. So I need to acknowledge not all family members from the same family had the same thoughts on what I was doing or which stories were in it. And so I, I want to be careful about how I also talk about including kin. Not every single family member known was part of this process, but I tried as much as possible to at least actively invite as many family members who wanted to be a part of it, to be a part of it. They're also always invited when I give book talks to attend the book talks, if they want to. And recognizing that that is also not a neutral act, to hear others tell your family's story. And so in thinking through far past the book to what does continued consensual collaborative work look like and do with one another, which is not just about what I do, but what my collaborators do, and how we negotiate this project together, past the publication date.

So the consent part for me is kind of bedrock. And I consider that a fundamental feature of accountability and the push that having Native American Indigenous studies and critical disability studies together is to think about who's most targeted by these forces of power and privilege and to follow their lead if they want to offer a lead on it, and to be able to point directly to places in the book (not just describing how I'm doing this practice) but actually doing this practice. Which is also about the language that got used. That the references to Canton Asylum, for instance, are only from the people who were detained there. There's a nickname for the institution that is abhorrent and racist, and still used by many people, and generated by the white staff members who supported this institution,
who made coin off of this institution and what it did to Native people. I don't use that term. No one who had kin detained at Canton Asylum used that name, and the relatives who are around now helped me understand whether 'grandmother' was an appropriate term to use for an ancestor or whether a nickname was appropriate to use or a combination, which helped me also hold more space for their personhood. And I think brought me back to being in relationship of my own with the people that I'm learning about, which is to say all of these people with all of their families that I'm continuing to learn about. And continues to press me to think about the distance between 'patient' and 'inmate' and 'person' and 'grandmother.'

It also, I'll note because it comes up with some frequency when I talk about the book, there are no photos just of the buildings. There are no photos of the superintendents. By design. If you go into the archives, those are the photos that most frequently appear. And so recentering to those who are at the center of the story, who were the most targeted by the forces of settler colonialism and racism and sexism and ableism, changes how we even imagine the space being taken up.

And I wanted only to include photos that the family members wanted me to include and to set aside photos that I had of people who were detained at Canton, but whom I couldn't find out exactly who they were. Where I couldn't find their family members. And that also meant that people who were not detained at Canton, but who played a role in re-storying this tale, who had photos available out in the world, I also wanted to talk to their kin if they had already walked on, to make sure that it was okay to use those photos. So I want to make the distinction or clarify that this isn't only about materials that appear in the National Archives, but contemporary materials that are available on the Internets and other places.

I'm wondering, because we've been talking about accountability and community building, Caroline, do you think you would be appropriate if we jumped to that question? Uh, but I know Susan, you were really excited about, about the relationship between accountable and accessible scholarship. And then maybe we can loop backwards to some of the questions that are a little bit more content driven about like a settler, ableism and pitfalls.

Caroline: I mean, Susan, I think you've been alluding to this throughout our whole conversation, but I'd love to, we'd love to hear you say more about the relationship between accountable scholarship and accessible scholarship. The floor is yours.

Susan: I love this question. I'm so grateful you posed this question. [laughter] I'm still mulling on it. I hope I'll be mulling on it forever. When I think about the scholarship and just knowledge sources in the world that have changed my world, a common feature is their accessibility. And I feel increasingly committed to practice as an historian, that if my work builds on the presence of people, I am accountable to them. If I claim disability historian and disability community as homebase, I'm accountable to it. If we create scholarship that is not accessible to the people who made our field possible, I think we are breaching a trust. And I want to call out to all folks who claim history (in the broadest sense of historian) to start with access as the practice and to imagine out what we get to be and what we get to learn.

So for me, access is one of the components of accountability. If we create work that builds on the presence of disabled people, which is to say the field of disability history, my hope would be that, as robustly as we are able, recognizing our contexts shift and options also shift, expand and retract, that the more accessible we make our work, the better our work is; but also the more we honor our ancestors from crip community. That part of what
disability continues to teach us is that access shapes who we've been, who we get to be in the now, and where we're headed: what we can become, how we can even imagine what we can become.

And I am excited to see the different ways that colleagues in disability studies broadly are expanding our own imagination now on what's possible in terms of access—not just as meeting regulations or serving a functional component. But access as pleasure, access as part of our caring for one another. And I think that deepens the stories that we look at from the past and how we treat them as, as kin in the broadest sense now, as well as scholars in the now. So access is fundamental in accountability. And when I think about accountability, I used to think of it as, as this somewhat daunting thing. How do I make my work accountable? But it's, now it's more of a friend. I think about the importance of colleagues and buddies from many different realms within disability world and outside of it. In Native American Indigenous studies and Native communities and outside of it, who continue to hold me and hold me accountable. And I, I think of those paired words as really important in these realms of access and accountability -- that for me to do this work requires a lot of care for self and for others. And that it's a deeply interpersonal and expansive web involved. And that being held accountable is part of that too. And thinking through the word choices, thinking through which sources, thinking through who and what's at the center, and for whom is the work.

We’re the three of us historians in that academic sense, training in institutions, publishing work in magnificent and fantastic ways, and also ones that are following a pretty well-worn path. And I, I marvel and am excited by the work that you're doing. And I think that well-worn path can bring us to many important places. I yearn, yearn to see history in all of the other places. I think about Penny Richards’s call to take over Wikipedia and to do chalk art on sidewalks to teach out, to have disability history exhibits at county fairs and at PTA meetings and all the other spaces that we actually inhabit in our lives. I think those are ways of expressing accountability to the communities where they are and expanding our understanding of access so that it's not only in -- goodness knows, I love Open Access works, I want more of them -- but access that's not only connected to the digital, and access that, that brings us back into relations with one another.

I don't know all the forms that that can take. I put it out there as an invitation for others to help us figure that out and to create it and to share it back. It's part of what I genuinely love about Disability History Association, as someone who's, who's watched it for a long time. It's exciting to see there's a podcast! It's really exciting to see all these different ways that we're, we're sharing a love of, of our history and recognizing that it is for a wider public as well as for ourselves.

Caroline: I mean, I don't have any particular wisdom to add to that, but I just have to say how much I want to echo that, Susan. And I have found that just talking to my students about how they like to encounter history, how their families encounter history is revelatory, right? They're learning and investing in history through TikTok, right? Things like that. And I just, I'm not saying we all need to start a TikTok [laughing], but it's something to think about, right? That, yeah, that in fact, they're already doing really incredible history in many ways and encountering history in really incredible ways. And we should be celebrating those.

Kelsey: I've loved this sprawling conversation that we've had about methods and ethics, accountability, access, history as care work and community building. And I, I know that our listeners will absolutely eat this up. Just devour it. It's just such a, such a dynamic
conversation. I do want to circle back to talk a little bit more about the stories that you were telling, that you were working through within, within your book.

I know that you mentioned this term settler ableism, and I’m wondering if we can slow things down and say a little bit more about what, what is settler ableism and how did you see it animating the stories that you encountered in Committed. More specifically, like, in your introduction, you share that Elizabeth Faribault, that for Elizabeth Faribault and her kin, pathological diagnoses obscured the violent disturbance of family and community health. And that's a direct quote pulled from your work. Can you say more about how these diagnoses enforced settler ableism? So yeah. Tell us what settler ableism is and the relationship between settler ableism and the, kind of, the diagnoses that were capturing Elizabeth Faribault and people like her.

Susan: I'm so glad for the chance to, to share in conversation about settler ableism. I want to give credit to Jess Cowing who first introduced me to that particular concept and, for me, particularly drew attention to the historical context around this thing we're calling ableism. And Jess and others stretch my own imagination of this, this force. So I have a working-ish definition of settler ableism. I, I would not proport to have a comprehensive definition. But when I think about settler ableism, I think about a system of power and privilege that places people and societies into a hierarchy. And the factors against which people in society are measured include very specific cultural notions of competency, and independence, linear progress, of competitive gain, material gain, among other features. We have related terms like fitness and normalcy that also cohabit. And then, of course, all of these values and concepts are anchored to particular times and places and people, but it's how they get deployed that gives ableism force.

And so if we take the example of Elizabeth Faribault, for instance, she wasn't only measured by Western biomedicine. Western biomedicine becomes an important tool in the arsenal of settler ableism, but her very being as an Indigenous person was pathologized. And that's larger than just a framework of Western biomedicine. This is where we get into settler colonialism and its own force of constantly erasing, eradicating, and replacing with a settler worldview and presence, and placing on top of an Indigenous presence a settler one, and claiming it as home.

So settler ableism is an offshoot, is a component of settler colonialism, as I'm imagining it at least. And it means that virtually anything that Elizabeth Faribault or others did, could be pathologized. So invoking this language of Western biomedicine and diagnosis to justify violent interventions in her life, in her family's life, in her nation's life and all other Native nations and individual people's lives. So using diagnostic labels strengthened the position of superintendents of reservations, for example, and their accomplices -- physicians, policemen -- to forcibly remove a person from her home and from her children and her spouse and her other kin. And then used again and again in different forms to justify sustaining that exile. And that exile is not only about Elizabeth Faribault being contained at Canton Asylum, but her kin on the outside being contained away from her or kept from her. And it's, it's that continued segregation-- with the goal of annihilation--that these institutions, and Canton in particular, were meant to hold people for the duration. So it shouldn't surprise us that the majority of people who entered Canton Asylum did not leave it alive.

And when thinking about the ways that ableism emphasizes that some beings are worthy and may continue to exist, and others may not, this is one of the manifestations of it. And it is always, at least as I understand this history, it is always interactive with the other systems of power and privilege that, that wrap around and through settler colonialism. And
so Elizabeth Faribault was not allowed to leave Canton Asylum, according to the superintendent, because she was incapable of taking care of her mother or children. And incapacity, incompetence is one of those key features of ableism, this belief in competency. So that was rhetoric used to justify keeping her—at the same exact time the superintendent had Elizabeth Faribault taking care of his family, his elderly parents, his wife and children in their bungalow.

And so I think about the ways that ableism is not merely discriminating against disabled people, which is one of the ways it has been articulated and was helpful in drawing our attention to disability discrimination. But in, I think in actual lived form, it's not only about this thing we call disability, but the ways that societies and dominant authorities from those societies have biologized social difference and justified the continuation of inequity and violence in the name of progress, competency, excellence, independence.

And I want to acknowledge, I can't wait to join with others, and there already are many who are paying attention to ableism. Caroline is one of them who has already taught me so much more about this important force in our histories, in our lives today. What else can we figure out or question about this? How else can we understand it? I feel like I'm early in that learning. I wonder whether our field is still somewhat early in our learning about it. And I know that we have so much more to learn. I would love to hear your thoughts, if you want to share any, on what your questions are, what you're thinking about ableism or settler ableism.

Caroline: Oh, Susan, goodness. Well, you've put me on the spot a little bit. I think the definition that you provided is a really, really good one. Understanding these kind of interlocking systems of power that benefited one another and the ways in which these ideas of productivity and self-government were often at the heart of that. And I don't want to, you know, flog my own research, but I'll, I'll mention that what I've also certainly seen is this kind of intersection of forces is not just limited to settler colonial contexts, but actually also is operating in explicitly imperial contexts as well. Like when the United States embarks of course on its construction of the Panama Canal. It also intersects very, very tightly with questions of land use and what it means to build a productive environment. And of course, Indigenous peoples are often sort of weighed and measured against particular Euro-American understandings of what it means to make productive use of land. And so this notion of evaluating Indigenous peoples as somehow incompetent and unproductive is going hand in hand with evaluating land as not sufficiently productive either, right. And so this is, when you bring up questions of kinship, right, what we're actually also understanding is that this evaluative system of settler ableism is not just evaluating Indigenous peoples as individuals, but also their relations with one another and indeed their relationships with the larger living world around them.

Susan: That's so helpful. Thank you for clarifying and expanding. And I think part of what's so exciting about these kinds of conversations and this kind of scholarship, is it, it's, it's reminding us that the contest, context itself matters. And I love that you're also teaching us to pay attention to our relationship to place and space. And that, you know, that's certainly core with Indigenous studies and Indigenous lives. And it's core, but perhaps in different ways for settlers across all identities. I can't wait for you all to continue teaching us more about this.

Kelsey: I know we initially had this question about Indigenous acts of resistance, how they were pathologized, and how pathology served a particular purpose for a settler-colonial state. I feel like you kind of already in the way that you were addressing that last question got at that a little bit, but I didn't want to completely remove the question if there was
anything else that you wanted to say about pathology as a particular, pathologization and medicalization as an instrument of the settler colonial state. If, if you wanted to say more about that and ways that you saw pathology serving a purpose, yeah.

**Susan:** Thanks Kelsey. There is one component of this that stays with me and I'll, I'll beg for your patience on this one. Among the things that concern me about many histories of institutions and of institutionalization -- going back to earlier things that we talked about -- that gravitational pull to align to the history of the institution itself and not to critically assess the project of coercively institutionalizing people in the name of medicine, in the name of many different things. But when I think about other histories of Canton Asylum and ones that are being told today, the tendency follows a recognizable pattern, which is: the story begins and ends when the institution opens and closes. That its opening was considered an expression of progress. Its closure was considered an expression of progress. And the ways that I think Western biomedicine, ableism, and settler colonialism, and this project called America that emphasizes exceptionalism and individualizes problems, buffers us from recognizing this longer trajectory of forcibly removing people and placing them in brick and mortar places and keeping them there as a fundamental feature of the United States’ history. It's part of what this nation does, has done, continues to do at exponential rates. And I think that challenges disability historians, other historians, folks who care about social justice, to push back against these parameters set by brick and mortar, set by institutions themselves. And to keep asking about the larger project of incarceration and the ways that, for me at least, when I began learning about the people who were detained at Canton Asylum, so much of the information was about Canton Asylum, not about the people. That’s a long pattern in histories of incarcerated people is that the people are rendered abstract or literally hidden by the institution itself. But that one of the hopes I have for disability history and for history more broadly is that we who practice it will not be seduced by the particular labels and types of institutions.

So that I think about the field of deaf cultural history, to which I owe so much, frequently focuses on boarding schools for the deaf, which have played a fundamental role in community, identity, history, and continuance to present day. But the story doesn't stop there. And many other brick and mortar institutions (I'm going to stay mostly with the brick and mortar and not get super abstract about institutions here) but the ways that people have been held in institutions is a fundamental feature of US history. And then it lands in particular ways with disability history. And it interlocks with other targeted communities. And it compounds on the communities that live multiple layers of that overlap. And so I want us to pay attention, for want of a better word, and goodness I hope we get a better word, transinstitutionalization as part of a process of settler removal.

So the story doesn't begin or end with the creation or closure of an institution. It also doesn't begin or end with a single person going into an institution and getting out or not getting out. But these larger networks of institutions as a way to mark people based on very particular ideas of what people are supposed to be and do. And then creating places to hold certain people because of those reasons and those values. And the impact that that has, not only on the people who are taken to those places, but back to kin: all of the people in their world in their time and all of the people in their worlds past that time. And so for me, that's part of the work that I hope we see rise even more and expand even more in our field of disability history.

**Kelsey:** I'm so glad that you brought up transinstitutionalization there because it really was a really beautiful and seamless segue. So you already answered the next question that I was going to ask [laughing], which is brilliant. But I loved, I loved what you were saying about kind of the challenges that come up around telling very siloed institutional histories of
these brick and mortar institutions, instead of thinking about larger projects of confinement, internment, isolation, and how even if these institutions were nominally or even functionally different, there was a relationship between residential schools and asylums that we should interrogate as being kind of twinned projects of settler colonialism.

Susan: Absolutely. I mean, I think about as just one example, when Elizabeth Faribault was confined at Canton Asylum, she was housed in a building with another extended kin named Nellie Kamespka, who was an age peer of Elizabeth Faribault’s adult children, young adult children. They would have known each other before either Elizabeth Faribault or Nellie Kamespka were incarcerated at Canton. It’s important that Nellie Kamespka had been sent to the Pipestone Boarding School as a young person. And at the school, among many horrific things that happened to her, was that she was not allowed to speak Dakota. She was forced to speak English. She became incredibly facile and gifted in written English, she was a beautiful writer, both in script and in content—and a force to be reckoned with in her own right. When Nellie Kamespka and Elizabeth Faribault shared space at Canton Asylum, Nellie Kamespka taught Elizabeth Faribault how to write in English. And it’s an act of kinship. It’s an act of resistance. I think it’s a statement of the impact of transinstitutionalization as well: that the knowledge and experience that people, people have within institutions carries to other institutions. And in this one instance, the resources that Nellie Kamespka had gained while being at a boarding school were then literally translated through kinship to Elizabeth Faribault so that she could write to her kin on the outside. That Nellie Kamespka could read aloud the letters that came in to Elizabeth Faribault before Elizabeth Faribault was able to write on her own. And the phrases that Nellie Kamespka had used in correspondence that you can find long earlier—when she was still in school—show up in Elizabeth Faribault’s letters later.

And the lived wisdom that Nellie Kamespka had as somebody who escaped the asylum, was recaptured, and brought back, but literally she brought the knowledge of how to escape and where to go. Which she conveyed to Elizabeth Faribault who used it pretty immediately afterwards. And in thinking about what happens when we center on people rather than institutions, we can see the place of institutions literally changes. That across families and generations, we can see different institutions showing up, rather than putting the institutions at the center and trying to wrap people within and around them. And that’s a move I would like, I want to study more and do more with, and I invite others to, to pursue it as well.

Caroline: Yeah, absolutely. Actually I want to ask Kelsey a quick question before we sort of pivot to our, I guess it’s our final question coming up. But I’m curious, Kelsey, about ableism and its power alongside disability, its intersections with other forces like racism, institutionalization, and also at the same time, centering on people rather than institutions. And I was thinking Kelsey, a little bit about your own work addressing some of this and also about what you’ve been witnessing as you’ve been, you know, wearing your many hats, right, and I’m just wondering if this is a shift that you’re sort of seeing happening in our fields from your vantage point.

Kelsey: Yeah. This shifts away from telling strictly institutional histories. I’m, I, I feel a strong desire in my own work to sort of deinstitutionalize histories of developmental disability or intellectual disability. It's something that I've noticed just when I was doing, like, preliminary secondary source research. I was initially surprised to find that a lot of the histories that I encountered about developmental disability were focused around brick and mortar institutions, and that the questions that I was asking about the racialization of -- I mean, I’m using a contemporary category of developmental disability and it's precursors -- was told through the lens of these institutions. And I, I’ve definitely been asking questions
about, are there other ways to ask questions about a diagnostic category? And I'm still sort of puzzling through sorting through how I want to approach that. But I know that I'm interested, very interested in thinking about the triangulated relationship between parents, children, and medical doctors. That's definitely what's of most interest to me right now, how people lived within and alongside diagnoses. Like, what is the social life of a diagnostic category? So yeah, that's something that I'm thinking about a lot.

And I have to say that I haven't, I do think that there's a shift. Like, I'm thinking even about like Emer Lucy's work. Emer Lucy, we interviewed on the podcast at, around this time last year. So like a graduate student who is also writing about the history of developmental disability, but through the lens of parent guidebooks and memoirs, so popular parenting literature, but also stories and narratives that parents wrote about raising children with disabilities. And I know that she's really actively contending with the difficulties around telling disability histories using source material that's not generated by disabled people, but is generated by caregivers. So I know that she, she is someone who has sort of modeled for me, what would, what would it look like to think about developmental disability beyond institutions, thinking about it relationally, how it impacts family life very intimately. Yeah, just some, just some thoughts that I've had roaming about in my mind.

Susan: It's such important work. I'm excited to see where it takes you and where you take us Kelsey, in thinking about these core components of people's lives. And I think about the, the important work that other scholars have done about parent advocates, for example, and the role in disability rights movements’ history. And I applaud the pivot that you're making, that I hear you making. That's not only about those particular public-facing policy-oriented endeavours and interventions, but how else can the presence of disability be experienced by the disabled person and by those who may or may not identify as disabled. Which has me thinking a lot about Alison Kafer's important work of political-relational theories of disability, and the reminder that we are all influenced by ableism, but differently so. And that it behooves us in disability studies and disability history not to lean so exclusively on the word 'disability' for the work that we're doing and the invitation to see what else is in the room. Can't wait to see what you teach us with this. Very exciting.

Caroline: It's just been so interesting to see this field grow and change over the many, at this point, many decades that it's existed. Not as many perhaps in some fields, but it's getting into the many decades era now and, yeah, it's, it's just really thrilling to see perhaps in a way that the, the thing that I think helped create this field in the first place, which is people working out of lived experiences, right, is kind of circling back and again, becoming something that is centered a lot in scholarship, right? And it's, it's just really lovely to see that.

Susan, can we ask you our final question - which is, speaking of the field continuing to grow and develop, my goodness, we would just love to open the floor to you to talk about any upcoming projects or exciting announcements or just whatever is coming up next for you that you would like to share.

Susan: What a gift. Thank you. So I am thrilled, like lit up like starbursts, about a special issue of the Disability Studies Quarterly. And I'm looking at two people who have been fundamental to this project [laughing], during this interview. It's a special issue that I had the privilege of co-editing with Juliet Larkin-Gilmore and Ella Callow, sparked in part by conversations with Caroline and Amanda Stuckey and Jess Cowing and others who share a deep interest in the overlaps of Indigeneity and disability and critical study. So the special issue focuses on Indigeneity and disability and among the things that I love about it is that many of the pieces, including Caroline's (I'll give a shout out), is collaborative work. And as
an historian, as a humanist, I'm distressed at the emphasis on the solo author. I think it's so destructive to our field, and not how we actually learn in the world, nor, at least in my case, how we do our best work. I get to have my name on the cover of a book, but it is in no way just mine, for example. And I love seeing what's possible from conversations like what we're having right now, and the kinds of written work that we generate when we're actually in conversation with others. And so a number of pieces in, in this special issue are collaborative pieces. Also intentionally there are lots of folks who would not identify as academics who are contributing to this piece. And I love that, and their works are fantastic. And selfishly, there are—selfishly for me—people that I've met because of the book project *Committed* who have contributed to the project, including a direct descendant of someone who was incarcerated at Canton Asylum. So please check out Anne Gregory's piece about her great-great-grandmother and, and Sarah Whitt—who's a terrific disability and Indigenous historian who is of Choctaw Nation—and is writing about the ways that Canton Asylum reflects the broader forces of settler colonialism in land dispossession, which is another way to think about institutions that I wouldn't know, except for Sarah's place in my world and in our field.

In addition, if I may continue to toot the horn of this awesome special issue [laughing], is that it was a really collaborative process. I loved the, the editorial team was really interactive with the authors. There were lots of back-and-forth (in the best of senses): lots of Zoom chats, lots of wondering together and not having necessarily fully formed projects from the start, but figuring out possibilities together, and works that are comparatively speaking short, not standard academic length, and overwhelmingly attentive to access. So the language that we use and how we use it, and incorporating gorgeous images with thick description built into the analysis. Thank you, Caroline, for modeling that. And getting to work with a super team at DSQ. So I’m also looking at you, Kelsey, for holding us across this process. It was a long time coming to get this one out into flight. And so looking forward to having it Open Access format, which is vital in that accountability practice and in reaching the people who made the project possible in the first place. I’m inestimably grateful to DSQ for having Open Access as the platform and the invitations to think more widely about what we get to teach each other, what we want to talk about with each other and to see where it goes, which is to say the setup for other issues that I know are in-process right now are thrilling to me as somebody who’s been around for a few centuries in this field. I can’t wait to see the next issue and the next issue, and the next issue teach us.

**Caroline:** Thank you so much, Susan. It's just wonderful to hear about it. And thanks for your kind words.

**Susan:** Thank you for what you both have done for that project [laughing].

**Kelsey:** We are so, so excited about your special issue, the Indigeneity and disability special issue at DSQ. We just were chomping at the bit to, to get it out there in Open Access format too.

**Susan:** I so appreciate that it's a ton of work. Like, there's the beautiful final product out in the world that, that's going to be terrific. And a great example of 'we don't get there by ourselves.’ This one has taken a lot of, a lot of hands and a lot of holding.

**Kelsey:** It really does foreground like the labor of producing a special issue, even if you're working – and I know you said that a lot of the pieces that are featured in your special issue are collaboratively written – but even if you're working with solo authors, I think it really exposes, like doing the work of, like, corralling and collaborating [laughter] with your contributors as a guest editor for a special issue, really like punctures the myth of, like, solo
authorship in a way that I think, it can be tedious and, and phenomenal in the way that it foregrounds that nothing is a solo authored work, that we're always writing in conversation and in community.

**Susan:** Exactly.

**Kelsey:** Thank you so much, Susan, for joining us today. It was truly a pleasure and I learned so much just being in dialogue with you and Caroline today. It was the perfect way to spend a Friday afternoon. And I'm really grateful for what I'm coming away with. It was really fortifying, like a nourishing conversation, so thank you.

**Caroline:** I echo that. And thank you so much, Susan, for your time, for your graciousness. It's just always a pleasure to be talking to you.

**Susan:** I’m nodding enthusiastically up and down, having experienced an abundance of friendship and learning together. Thank you both!

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