

Disability History Association Podcast
Interview with Andrew Hogan
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Kelsey Henry: Hello and welcome to another episode of the Disability History Association Podcast. I'm Kelsey Henry.

Emma Wathen: And I'm Emma Wathen.

Kelsey Henry: And it's our pleasure today to be in conversation with Professor Andrew J. Hogan. Andy is the Henry W. Casper Professor of History and Director of the Science and Medicine in Society Program at Creighton University. Andy, thanks so much for joining us today.

Andrew Hogan: Thank you for having me.

Emma Wathen: Andy, can you start by telling us about your path to disability studies and disability history? We know that you arrived in disability history by way of histories of science and medicine, and we're curious about how this route to disability history has influenced how you position yourself within the field.

Andrew Hogan: Yeah, so my first book and my dissertation project looked at the history of medical genetics and at the ways in which certain genetic conditions came to be delineated, both clinically and on chromosomes, and became associated with chromosomal locations and diagnostic methods associated with chromosomes and chromosomal analysis. And, you know, as I was giving these talks for my dissertation in my department and conferences and other places, people kept asking me what is the disability perspective on these issues? And honestly, as a twenty-something, able-bodied white man, I hadn't really thought about that. And I really appreciate that push. And it got me really thinking about what is the relevance of these topics that I'm studying? And you know I was looking at conditions like Fragile X syndrome and Prader-Willi syndrome and DiGeorge syndrome, and at this time trying to understand them from a disability perspective additionally. And so this really sort of opened up my perspective on these issues and led towards the second book.

Kelsey Henry: Perfect, thank you so much, Andy. Your first book was *Life Histories of Genetic Disease: Patterns and Prevention in Postwar Medical Genetics*. And your second book, which is our topic of conversation today, is *Disability Dialogues: Advocacy, Science, and Prestige in Postwar Clinical Professions* - which was published by Johns Hopkins University Press in 2022. So already, just looking at the titles of those two books, we can kind of see this transition from thinking about medical genetics into thinking about the implications of some of the initial research that you did for that book, and the way that it shaped questions that you were asking about disability advocacy and clinical professions in

the postwar period. I'm wondering if you want to say just a little bit more about that transition from the first book to the second, and how the second book project took shape.

Andrew Hogan: Absolutely. I definitely approached disability history from the perspective of a historian of science and medicine. And over the course of time, disability history and that literature, and that perspective, which is in many ways more activist and more focused on advocacy, began to influence what I was doing. And so, while my questions about, how is this knowledge produced and how is it interpreted, are still part of the second book project - as they were part of the first book project - certainly the voices of advocates and of disabled people, and of the parents and family members of disabled people, became more prominent as the book project progressed. And I think, more so than my first book, my second book was really rooted in archival sources. My first book relied a lot on published literature from medical genetics and other fields like that. But it was really wonderful to find so many really productive and inspiring archival sources to work from which brought so many new voices into my story for the second book project. And one of the first ones that really sort of got this project rolling I came upon right as I moved here to Creighton in Omaha, Nebraska, about 10 years ago, and that was the paper collection of a psychologist and disability advocate named Wolf Wolfensberger, who was a German immigrant who came over to the United States after World War II as a young man. He did a PhD in clinical psychology, and began working in various institutional settings and really seeing and being quite troubled and offended by the ways in which people in these institutionalized settings - these were adults in psychiatric contexts mostly - were being treated and understood and introduced new ways of thinking about this, of normalization and of deinstitutionalization. And he happened to have extensive archival records which, since he spent a little bit of time here in Omaha as a Professor at the University of Nebraska Medical Center, ended up at this particular archival site. And so that really got me started on looking at the history of psychology and its relevance to disability.

I also was initially quite interested in issues around naming conditions. And this came out of my first book project, too. Like, where does the name Fragile X syndrome, or Prader-Willi syndrome, or DiGeorge syndrome, come from? And what I learned is that in a lot of these circumstances these were not the first names given to conditions. They were names that were adopted later, in part because of advocacy. Parents were in many ways confused by or offended by the initial name, and so there was a desire to find a more neutral sounding name, a more honorary name, an eponym was often favored by parents, and other advocates for disabilities, as opposed to say, a name which is rooted in some sort of chromosomal marker or something like that, right. And so, seeing the role of advocacy and the perspective of non-biomedical voices in this process was another sort of important connection and inroad to the second book project.

Emma Wathen: So in *Disability Dialogues* you look at post-WWII shifts in how three clinical professions, and that is clinical psychology, pediatrics, and genetic counseling, treated disability in clinical practice and participated in disability-related advocacy, sort of like what you just mentioned. Why did you choose these three particular fields? And relatedly, why did you decide to focus on the treatment of intellectual and developmental disability as opposed to psychiatric, sensorial, or physical disabilities in the story that you were telling.

Andrew Hogan: The fields, you know, as these things go, kind of came about over time as making a lot of sense coming out of my first project and based on the sorts of sources that I found available. I was led in the direction of psychology, in part by the Wolfensberger collection. And that really sort of opened my eyes to the relevance of psychology as a field that, especially clinical psychology...Historians of science have looked at psychology a lot as a science, but historians of science and medicine have rarely looked at clinical psychology, especially after World War II, as a field. And so this kind of got me started on looking at fields which are underrepresented in the literature of the history of medicine to begin with, and this is true of pediatrics and genetic counseling as well. And so that was definitely an appeal of each of these fields. I have to say that Alexandra Stern's book *Telling Genes* which came out in, I believe, 2012, certainly influenced some of my decisions as well in this direction. And talking to her about it, she was very supportive that there was a larger story to be told about the history of genetic counseling, which she covers in that book, and which is an obvious sort of connection to my first book project, as well as how psychology influenced genetic counseling, and she covers that in her book, and so that made a lot of sense. And pediatrics as well - a lot of the conditions I looked at in my first book were pediatric conditions that affected adults as well, but they were diagnosed in the pediatric context. And since I was coming out of the first project with a focus on medical genetics and associated developmental disabilities, it made a lot of sense to focus on these fields which were particularly sort of interested in those areas. And so in many ways the focus on developmental and intellectual disabilities is a continuation from the first book's focus. And that connected quite well with the fields that I was studying, both in terms of clinical psychology, pediatrics, and genetic counseling. But I'll also say that while the book tends to focus more on intellectual and developmental disability, sensorial and physical disabilities do play a significant role in the book to the extent that a lot of the disability self-advocates that I highlight have those forms of disability. They are blind, they are deaf, they have physical disabilities. And so their stories are definitely part of this history as well in terms of thinking about advocacy. When it comes to developmental disabilities, there's certainly self-advocacy among people with developmental disabilities, but more often there is advocacy by their parents, by their siblings, by other people who are closely related to them, and so that becomes part of the story as well - when self-advocacy becomes sort of part of my focus.

Emma Wathen: It's amazing throughout the book, seeing all of these differences and parallels play out in these 3 different fields. I think that one of your most fascinating arguments is that the medical model of disability is somewhat of a straw man that does not consistently map onto clinical understandings of disability that you found in your research. Instead, you argue that the medical model was deployed as a critique of clinical practice, either by clinicians arguing for reform or by disability scholars. Would you be willing to say more about the heterogeneity that you found in postwar clinical perceptions of disability, perhaps drawing from a few of your case studies.

Andrew Hogan: Sure. And you know, what I'll say is that, as is often the case, we begin by, as historians, trying to do a little bit of a deep dive like, what does this term really mean? And how has it been used? And where did it come from? And when you start looking at the medical model as a term and as a concept, what you discover is that it was initially

used by especially psychiatrists, to critique the area of medicine, whether that be critiquing institutionalization, critiquing understandings of psychiatry and the practice of psychiatry, the lack of holism in psychiatric practice and approaches. And you very rarely find anybody sort of defending the medical model in an explicit way, saying, the medical model is what we do, the medical model is an explicit, intentional way of practice. What is usually brought up, whether by a clinician or later by a disability advocate, is a critique of what is viewed as wrong with medicine. And I think that historians, as well as sociologists, are sometimes misleading themselves by sort of approaching the medical model as an actor's category, or really not as an actor's category, like as one that describes something that people understand themselves doing. And when we sort of look at the, as you say, the heterogeneity of how this is applied, you start seeing instances in the history of disability, of how physicians, clinicians, approach disabled people and disabled patients. And one of the most striking sort of stories which I start off one of my chapters with is that of Margaret Giannini, who was a young pediatrician back in the 1950s at the New York Medical College. And what she discovered was that there were lots of families who had children with disabilities in New York City at this time, who could not get any medical care at all that. And I'm not talking about medical care for their specific disability, I'm talking about like, they had a cold and they had no place to go. They wanted a vaccination - they had no place to go, because pediatricians just wouldn't see them because they had Down syndrome or whatever form of disability. And so she started a clinic, seeing children with disabilities a few days a week, and then eventually this expanded into an everyday, full time kind of thing. And so this tension around, you know, where do children, where do adults with disabilities fit within the medical model, if you will, is there and needs to be renegotiated, especially as deinstitutionalization begins to take place in the 1950s, 1960s, 1970s.

I also saw a lot of narratives coming out of psychology where you have able bodied psychologists, who are rehabilitation psychologists, who are very interested in the concerns and the challenges that disabled people face, but still basically feel like disabled people can't really advocate for themselves, that ultimately able bodied people have all the power in the world, and therefore able bodied people need to be the advocates for disabled people. And you know this is another sort of, what we would today understand is a backwards perception of the potential for disability advocacy within the medical and psychological world. There's also a real lack of a sense of the possibility of disability pride. And it's not until the 1990s and 2000s that we really see a sort of pushback on that, both outside of and within medicine. To kind of say, you know, having a disability is something that you can be proud of. This is an identity which can be important to people, which can be not just a negative thing, or not just bad news or not, just something that you need to be ashamed of, or hide, or try to cover up. And this also comes from some important disabled clinicians, especially working in psychology. People like Carol Gill, people like, more recently, Erin Andrews, who is a psychologist who has written about this and tried to create a model for understanding the role of disability pride within the broader context of the social and the medical model, what she calls the "diversity model."

Kelsey Henry: Thanks, Andrew, that's a really helpful breakdown. In your exploration of that heterogeneity within the clinical treatment of disability in the fields that you're looking at, you tell a really fascinating story about the role that scientific expertise and concerns

around professional identity played in the success and failure of alternative models of disability. So I want to dig into that part of your story a little bit more. Emma and I are both trained as historians of medicine and science as well. And we really appreciate your attunement to issues of professionalization and prestige in genetic counseling, clinical psychology and pediatric medicine, and the influence of these complex professional motivations and deterrents when it came to adopting more inclusive or socially progressive models of disability in each of these fields. I'm wondering if you can walk us through some of the professional motivations and concerns that clinicians in these fields shared related to disability, inclusion, and advocacy, and highlight essential differences in how these conversations developed in each of these fields.

Andrew Hogan: I think it's important to sort of recognize that, especially when we're looking at clinical psychology and genetic counseling, that these are largely postwar fields - or at least they grew significantly during the post-WWII period, they existed to some degree before that. But the reason that they grew, by and large, was to respond to disability as a problem, and to address disability as a problem in order to diagnose it, to ameliorate it, to prevent it. And so there's something fundamental to medical psychology and genetic counseling, and to some degree pediatrics, in preventing or getting rid of, or identifying and trying to ameliorate the "problem" of disability. And so disability views which were more positive and inclusive very much challenged this expertise, and it challenged this expertise in part because, especially when you come to clinical psychology, for instance, the preferred approaches tended to be quantitative, tended to focus on things like measuring IQ and thinking about a statistical analysis of IQ, or assessing various strengths or weaknesses in terms of one's daily activities. But all this was done within a clinical setting, and psychologists felt comfortable, being able to do these things. But as new disability perspectives and insights came in during the 1980s and 1990s there was a push to move away from IQ as sort of the number one compelling measurement for making sense of disability, intellectual disability in this case. There was a push to really focus more on how patients cope outside of the clinic, and what sorts of supports they need outside of the clinic, which was not something that clinical psychologists were used to measuring or paying attention to, and it meant that other forms of expertise and knowledge and experience were beginning to challenge their dominant role and to undercut the sort of quantification and diagnostic and classification processes that they knew so well.

And so new disability narratives and perspectives, ones that were more optimistic and inclusive and positive, were challenging for a number of clinical psychologists in this period. And certainly the prestige of their field was associated with their more, if you will, objective approaches and quantitative approaches. There was a physics bias here and a desire to be able to do things like a physicist does things but new disability narratives and perspectives and approaches challenged that. I saw this and assessed this coming through in pediatrics as well, that pediatricians who focused on disability in the late twentieth century sort of broke down into 2 camps. One of them tended to be more focused on what they call "neurodevelopmental disabilities," and the other tended to be more focused on developmental and behavioral disabilities. There's a lot of overlap between these 2 areas, but there was significant epistemological differences in terms of how they approached disabilities. The neurodevelopmental disabilities people really wanted to follow this prestige

path, if you will, of other subspecialties and pediatrics that had gained a lot of status during the postwar period, like cardiology or nephrology or something like that. And when they looked at it they said, well, the thing that these fields have that we don't have is an organ, and so we need to have one. And so we'll go with the brain, and we'll study disability through the lens of brain damage, basically. And just presume that all these different forms of disability that we study, whether it be intellectual disability or autism or cerebral palsy, or what have you, are basically fundamentally the result of brain damage. Now, of course, from a disability perspective, this is a stigmatizing viewpoint to have it. It suggests that there's little opportunity for development. It suggests a pathological basis for disability in ways that are problematic. It suggests a level of severity that can lead to significant degrees of hopelessness. But from the perspective of these pediatricians who are trying to bring status and prestige to their field and make sure that it was recognized in the same way as cardiology, it made a lot of sense as a strategy.

In genetic counseling, I think there was a real tension between...are genetic counselors mostly skilled in genetics or counseling? And genetics was the sort of biomedical understanding of disease, of disability, where it comes from, and how it's passed down through the generations, and what causes it, and what the risk factors are, whereas counseling was perceived as more, how do we talk to patients? And when I interviewed genetic counselors there were sort of 2 perspectives on what the counseling aspect of genetic counseling meant. Some of them said, well, the counseling aspect is just that we happen to be good communicators, that we're good at speaking to our patients in ways that make them understand the genetics. And that is true, and a lot of pediatricians and other people, other physicians, will tell you that genetic counselors are very skilled at this, and this is a very important thing. Now, other genetic counselors would say, well, actually, the counseling is really something bigger than that. It's more about sort of therapeutic counseling or psychological counseling, that there's another level of going deep and really trying to understand people's concerns and issues and helping them work through those things. But by and large the genetic counseling field has distanced itself from that more psychological approach, therapeutic approach to counseling, and focused itself on the genetic knowledge and communication focus. And I think there's a lot more room for genetic counseling to sit with disability and become a disability advocacy-oriented field, if it's more focused on the counseling aspects - the psychological aspects of genetic counseling - as opposed to communicating genetic knowledge aspects of genetic counseling. But once again the prestige, the value of genetic counseling to medicine, the likelihood of being compensated - of getting an hour of time to meet with patients - was rooted in their genetic expertise as opposed to their counseling expertise. And so there was a tendency by the national organization [Formal Name], and by a lot of genetic counselors, to sort of shift their identity in that direction, more so than the therapeutic counseling direction.

Kelsey Henry: This is a very specific follow up about genetic counseling that came up for me. I remember reading in your book that initially medical geneticists - before genetic counseling became, at least for a period of time, more psychologically and therapeutically oriented - medical genetics was more male dominated. But we know that genetic counseling is fairly female dominated. And I'm curious, in this negotiation in the genetic counseling field between a professional identity that is more geared towards counseling and having

therapeutic conversations with patients versus a practice that is more closely tied to genetic science - a negotiation over the softness or the hardness of the field - the way that gender came into those conversations.

Andrew Hogan: Yeah, so the genetic counseling field evolves over time from being, in the mid-twentieth century primarily a field made up of MDs and PhDs, who call themselves genetic counselors, to, after 1969, the creation of the first master's level of class in genetic counseling at Sarah Lawrence College - which is an all-women's college at this time - and is specifically trying to identify new student populations, attracting women who probably already have a college degree, who perhaps have been out of the workforce for a time to come back to college and do a master's degree. So this and then that model spreads across the country during the 1970s and 1980s. And so this is how genetic counseling becomes a female dominated field. Initially, the men who call themselves genetic counselors, there's a lot of tension between them, but they essentially ceded that term eventually and became medical geneticists as opposed to genetic counselors.

I would say that gender plays a role in this issue, less so because of the history of genetic counseling per se, and more so because of the structure of the medical world more broadly. The medical world in the late twentieth century is dominated by white men who have particular perspectives on women's and men's roles in healthcare and which are most prestigious. And certainly there is a lot of emotional labor rooted in genetic counseling. You can actually go all the way back to Charles Bosk's really famous book [*All God's Mistakes*] about the history of genetic counseling to see the ways in which emotional labor, whether performed by a man or a woman, in the 1970s is a significant part of the field and lowers its status whether a man or a woman is doing it. And so I think there was a desire to move away from that emotional labor and to increase status. And this is among the female leadership of the field. ~~In order to and~~ They would pursue that by becoming genetics experts instead of counseling experts. And so I think it happens in the broader sort of gendered framework of the American healthcare system and roles as opposed to perhaps a tension that exists in that transition period between being a male dominated field and a female dominated field during the 1960s and 1970s.

Kelsey Henry: Yeah, just as you were talking, I was curious about, what are the parallels here, or are there parallels in terms of gender and professionalization and prestige in the field of genetic counselling, and perhaps, like what you see in the history of nursing in the twentieth, moving into the twenty-first century. In terms of nursing being a female dominated and feminized field, and having women who are nurses desiring more prestige within that field, and wanting to acquire that through securing a status that is more clinical and scientifically oriented. That's really helpful. Thanks. So I also wanted to draw our attention towards another word that comes up a lot in your book which is "jurisdiction," which maps onto some of the conversations that we've already been having about expertise and professional identity and the role of severe disabilities or assessments of severity in securing and maintaining clinical jurisdiction over certain intellectual and developmental disabilities. So we're curious about the relationship between clinical demarcations of severe disabilities in pediatrics, in clinical psychology, in genetic counseling, and the role that quantified severity played in sketching the limits of the social model and the inroads that it

could make in clinical medicine. [We're also curious about] the role that these assessments of severity played in reasserting clinical authority over disability. Can you say a little bit more about that?

Andrew Hogan: Sure. As I researched this book and read all these different perspectives on disability, and how they evolved over time, and how disability advocacy evolved over time, the relevance of severity as a concept became increasingly obvious and relevant to me in my analysis. And here I'm drawing primarily on Robert Cooke who was a pediatrician, mid-twentieth to late twentieth century pediatrician, who had 2 children with significant developmental disabilities. They had Cri du chat syndrome. This wasn't initially known, and he became a disability advocate working with the Kennedy family, among other things, as a result of this. And he wrote some about severity, and he made this important point that severity is in many ways an imposed status. It's a relative thing, especially when you're thinking about a newborn or a young child with a "severe disability." Our interpretation of the severity of their disability isn't based on their own experiences, it's based on our experiences that one can really only understand something as severe in comparison to something else, and if you don't have a basis for comparison then there isn't really - it's a value judgment, right? And so he - Cooke and others - sort of made this point, and argued for the need to be more optimistic about children with significant developmental disabilities and treatments for them. Because if you dismiss a condition as severe, as was the case with Down syndrome until the 1970 and 1980s for sure, then you tend not to treat people very well. You're very hopeless about their treatment, and this leads to things like institutionalization. It leads to things like not doing lifesaving heart surgeries, even though you know that they can extend the life and quality of life of somebody. Just because you think, well, it's not worth the resources or the time or the effort, because it's too severe of a condition.

And this also plays out in the ways that different sort of subsections of clinical psychology and pediatrics demarcated what their jurisdiction was. Going back to my explanation of the neurodevelopmental disabilities people versus the developmental and behavioral disabilities people in pediatrics, the neurodevelopmental disabilities people try to claim a jurisdiction over brain damage as they defined it, but also over "severe" disabilities. And that sort of became what counted as theirs, whereas the behavioral and developmental people were increasingly interested in the forms of disability which were more common and less severe things like ADHD, or less significant, like certain forms of autism among other things, behavioral differences, things like that. And so this became a dividing line that really divided up professionals, but also divided up children and patients in different categories, I think in nonproductive ways because it certainly encouraged some people to be treated one way and often in sort of more biologized ways, pathologized ways, less optimistic ways, and other people to be treated in sort of more optimistic ways. And yeah, this is the case in psychology as well. There was a similar sort of divide that opened up in the area of intellectual and developmental disabilities in psychology - a sense that certain interventions were justified by the severity of disability, and certainly other historians have addressed this. The ways in which electroshock treatments were used, or other forms of punishment were used in the 1960s and 1970s on children with autism and other conditions, because their conditions were viewed as so severe as to essentially justify these violent interventions

and assume that the only way to have a breakthrough, or to prevent these children from engaging in self harm was through punishment as opposed to positive reinforcements.

Emma Wathen: This conversation has really helped highlight for me all the different negotiations that are happening over naming, whether it's of positions like "genetic counselor" versus "medical geneticists" or descriptors like levels of severity, as you just discussed, or conditions like Fragile X syndrome. I know you spoke earlier about how disability advocates help transform these fields, for example in pushing for new names for some of these conditions. And something that Kelsey and I found especially exciting and unique about your work is its focus on disabled self-advocates who are also clinical practitioners. Can you say more about the distinct lineages of disabled self-advocacy that was spearheaded by disabled practitioners themselves? And did you find any examples of coalition building among disabled practitioners across these clinical professions.

Andrew Hogan: I would say that when you look at the three fields I studied the numbers and the opportunities for disabled clinicians to first of all have a shot in those fields, and then to become advocates in those fields, was widely variable. In smaller fields like - and more medicalized fields - like genetic counseling and pediatrics - the road was lot harder for someone with disabilities to enter the profession for a variety of reasons. In genetic counseling there was a general sense that it was problematic to have a disabled genetic counselor because they might be seen as biased, especially since so much of genetic counseling was about diagnosing and preventing, through abortion, various forms of disability. Would patients, would pregnant couples, trust this person to be non-biased. And this was an interview question that would come up all the time well into the 2000s. In pediatrics, certainly to become a pediatrician, of course, you have to make it through 4 years of medical school first, and there are a lot of barriers to disabled people making it through medical school. A lot of expectations to be able to perform certain tasks that are completely unnecessary to be a practicing doctor in most specialties - things like surgical tasks and things like that. And so there are fewer people, first of all, who can be self-advocates in these fields. So this is hopefully beginning to change somewhat. Psychology is a much larger field, a much more diverse field. And so there are certainly more disabled psychologists out there, and this helped to create, over the course of time going back as far as 1970s and 1980s, a contingent of disabled psychologists who were able to take on institutionalized roles to advocate for themselves and for disabled people. and I described some of this in the book through the work of [Alice Rieger](#) and other people like that. But there was still a lot of discrimination. A prominent example of this was Irving King Jordan, who was the was a deaf psychologist, and the first president of Gallaudet University. He became deaf as a young man and he went from essentially being seen as a promising future psychologist to somebody who shouldn't pursue psychology, because that's not something that deaf people were allowed to do from the perspective of the field.

There are a number of self-advocates, especially in psychology, who were able to succeed in the field and who are able to begin to reshape some of the perspectives and narratives in the field. I highlight Carol Gill, who really introduced in the 1990s more positive perspectives on disability today - we would call this disability pride. and she certainly influenced many other psychologists. I mentioned Erin Andrews, who is a younger

psychologist today who is writing about this and who has developed and really sought to introduce the pride-based models into understanding for psychologists about disability and how it should be interpreted. One person who comes up throughout the book and really had her hand in all three professions - and this sort of answers your coalition-building question to some degree - was Adrienne Asch. And Adrienne Asch is really a fascinating figure who started out in psychology and wrote as a psychology student in critical ways about how the field was dismissive of disabled people. And then eventually got interested in bioethics and specifically prenatal diagnosis. And so she started talking a lot to genetic counselors and to pediatricians, especially pediatrician-medical geneticists, about the problematic views of disability within these fields, the ways in which these views about disability and the acceptability of prenatal diagnosis and prevention was in and of itself a discriminatory practice. And so Adrienne Asch was really an important figure in both bringing disability narratives into multiple health professions as well as in mentoring students with disabilities. She was blind and I spoke with multiple blind clinicians who knew her and were mentored by her and, in one case, were discouraged from going into genetic counseling because...they did it anyway. But she said, well, why would you want to do that? They're just eugenicists. And so, you know, she had her own quite negative perspectives of all of these fields, but she was also deeply influential in shaping the viewpoints of people who would listen and who were willing to listen in these fields to try to make them more disability-conscious clinicians.

Kelsey Henry: Thanks, Andy. I'm really curious about when, where, and to what extent were clinicians who became disability advocates carrying out their advocacy beyond the clinic. When clinical care providers became disability advocates how did that modify their role as clinicians? So this is a question about, within and beyond the clinic, what did disability advocacy look like for some of the clinicians and clinical practitioners that you studied

Andrew Hogan: So by and large I would say, and I think we're all sort of guilty of this, that clinicians, whether they were disability advocates or not, tended to stick to their expertise, and tended to stick to the sorts of spaces in which they were best understood and most respected. And so when I look at, say, clinicians who happen to be the parents or the siblings of someone with disabilities, they would have an advocacy role, but that advocacy role would often be as an expert pediatrician or an expert medical geneticist, or something like that. They would push importantly for better access to training programs for disabled people. They would push for new guidelines about how you offer a diagnosis to a couple who has just had a child with Down syndrome. They would push for roles for pediatricians that were more in line with being an ombudsman, and sort of offering lots of oversight and holistic support for parents of children with disabilities. But there certainly were examples that I found of. Disability self-advocates, as well as the family members of disabled people, who did reach out more into the community in various ways - especially with joining advocacy groups, became leaders in advocacy groups like Down syndrome foundations. Whether that be at the national or the local level, things like that, though still often they did so in sort of an expert role. By and large it was unusual to sort of find situations or accounts of somebody sort of going in the community with the desire to play a greater disability advocacy role and doing more to listen as opposed to sort of teach, if you will.

I think that all of us who are professionals, in our own way, have trouble with this. So [we] have trouble with sort of taking off our expert hats in various community situations and seeking to learn as opposed to seeking to bring our expertise, our very well intentioned expertise, to other communities, right? But I think a really important role of disability self-advocates within clinical professions was in mentorship of the next generation of disabled students. [For example,] opening doors that they felt were closed for them, trying to create more institutionalized norms around accommodations that didn't exist when they were students, sort of trying to help people in the various stages of health professional's training, which involves both the didactic stage - which some disabilities may pose challenges for and others don't - and then the clinical stage which can be a whole different set of issues, strengths, and challenges that are faced by disabled students. And, I mean frankly, it's also really important that these individuals who have made it in their professions as disabled people prove that it's possible - that they can be strong mentors and strong role models for students and open up a sense among their able-bodied colleagues who may have their doubts about the next disabled student that these things are possible. And that supports can be given to make things work really well, and that a disabled student can offer a lot to patients that perhaps able-bodied practitioners don't.

Kelsey Henry: I want to zoom out a little bit and ask about the impact of policy level changes and the legal landscape in the postwar period, with the rise of the disability rights movement, the impact of those larger social and political changes on the story that you're telling in these clinical fields. Emma and I are wondering to what extent did you find that landmark legislation, including Section 504 and the Americans with Disabilities Act, and major infrastructural shifts like deinstitutionalization, to what extent did they really make substantial inroads in either shifting clinical perspectives on disability or diversifying clinical professions with more disabled practitioners. And if legal and infrastructural shifts didn't make substantial changes in paradigm shifting these fields, can you say more about what prompted change, however small, in each of these fields. You've kind of alluded to this already, but I'm wondering if you can address this directly with us.

Andrew Hogan: Yeah. What I saw was with new laws, like Section 504 [and] the ADA, it certainly opened up spaces for new discussion. It forced conversations among administration and leadership that wasn't otherwise happening, [instilling] a sense that these students who have disabilities may come knocking on our doors and we're gonna must figure out what to do about that. But does it change recruitment patterns? Does it change accommodation patterns? Does it actually change the sort of technical standards that exist within a program that can define whether or not a student with disabilities will be accepted or allowed to finish? Not as much as you might think. Not that these laws were not important, and not that they didn't help to change the narrative and the perspective of people, but often professional organizations interpreted them in the narrowest way possible. They didn't see them necessarily as invitations to greatly expand disability or rights or inclusion within their profession. They saw them as legal barriers that they needed to carefully work around so as to not get sued, right? And so I would say that these laws had long term impacts that were very positive and expansive, but that the immediate reactions

and even sort of the advocacy that directly tried to draw on their existence was quite limited in its effects initially. It's what I saw in psychology in particular.

That said, I think... well, to shift more to the infrastructural question around deinstitutionalization, I think that deinstitutionalization played a significant role in shifting what professions viewed themselves as responsible for disability. Deinstitutionalization really sort of shifted the place of especially childhood disability from psychiatry, who, of course, psychiatrists primarily ran institutions in the mid-twentieth century, to pediatrics who had their place more in the community. And so as deinstitutionalization is happening or is being pushed for in the 1960s into the 1970s – and this is deinstitutionalization of children and adults with developmental disabilities more so than psychiatric conditions, which happened earlier - there is a shift among pediatricians in trying to say, well, okay, these patients are now gonna be part of our communities. Not that they weren't before, but we have a greater sense of responsibility now. How are we going to manage them and manage their parents and demonstrate our professional role in caring for them? And so certainly it changes sort of jurisdictional questions and questions of who...what patient populations are we responsible to serve, once you have this deinstitutionalization process really taking place by the 1970s seventies.

So another law that's relevant here is the Education for all Handicapped Children Act of 1975. And this act that we know today as the IDEA Act is something which is pushed primarily by special educators in the 1970s. And special educators really sort of carve out a particular role and importance for themselves in the enactment of this law, and pediatricians totally miss the boat and don't see it coming. And then all of a sudden, once the law is passed by Congress and enacted, they find that they have no real role for themselves in the enactment, like they don't - there's no money in it for a pediatrician to play any role in in diagnosing disability for the most part, even though that would be relevant to how a child is treated within the school system. And so certainly these laws do...depending on who promotes them, and what the words are, and who gets included and who doesn't get included, definitely influences the status and the jurisdiction of these professions and leads to moments of severe concern that they have been sort of left out, if you will, of the newest thing.

Emma Wathen: Let's switch gears and talk a little bit about your source material, because it's very interesting. In addition to working with archival and published sources, you've also conducted 75 oral history interviews with disabled self-advocates, clinical practitioners, and family advocates. Could you tell us what you learned from adopting an oral historical approach that would not have been apparent to you otherwise.

Andrew Hogan: Absolutely. I think that one of the joys of studying the recent past is the ability to talk to your actors, and I really value that, and I think it really offers perspectives and connections that one can't really hope to get from published sources or archival sources. There are so many silences that exist both in the archive and in the published literature. There are so many things that go unsaid in scientific and medical literature in particular - the things that you can't say, the motivations that you can't describe, the reasons why you did this thing, or why you came to this conclusion, or why you chose this

particular wording or approach, just don't have a place, unfortunately, often in the scientific and medical literature. And so getting the story behind the story is a huge part of what you get from oral histories. I spoke with a number of disabled clinicians, and I don't think there would be any other way that I could have really learned in detail about the challenges and the strategies that these clinicians developed in order to succeed in their training programs and faced once they graduated and sought a job or sought to advance their career, among other things. When it comes to clinicians and scientists, one really gets a stronger perspective on some of the polarization that exists within these fields when you talk to somebody. Because they're not gonna say that necessarily in the literature that, you know, there's these two camps who have these two views and this is why we dislike each other. And this is what we're trying to do in order to maintain our jurisdiction and to prevent them from having any sort of success in in advancing themselves, right? You also learn a lot about some of the less than objective approaches that lead to new guidebooks or new classification systems, and how those sort of ambitions inform the approaches that are taken, and then are perhaps undercut by another group of people who say, well, that's not really the way you're supposed to do it. And then learning about some of the negotiations that come about in in finding a way to bring together disability positive narratives with the more sterile and objective and quantification-focused language and logic of science and medicine.

Kelsey Henry: We'd love to hear a little bit more about where this project ended for you. What were the culminating takeaways? So by the end of the book you argue that increasing the representation of disabled practitioners in clinical science and medicine would make a tremendous impact on diversifying perspectives on disability in clinical fields. Can you elaborate on this take away? And then how do the disabled care providers you've spoken with or encountered archivally self-conceptualized the unique perspectives that they can bring to the table that an able-bodied person can't.

Andrew Hogan: Well, I've already talked a little bit about some of the advantages, some of the momentum, if you will, of having more disabled practitioners, in terms of clearing the pathway, opening doors, providing mentorship, and expanding the presence of disabled practitioners in various fields. I think that's very important. But one can also look at this from an epistemological perspective that so much of the barriers to, and the resistance to new, more positive, optimistic, inclusive disability narratives and views within the clinical professions are sort of rooted in concerns about prestige and concerns about identity. And I think that in order to speak to these perspectives and to challenge them and to help them to evolve in effective ways, you sort of needed to be able to speak both languages, right? You need to come into the situation both with the experiences and the perspective of a disabled person living in American society, as well as having the language and the knowledge and the background and the experience of going through training and knowing what it means, what the true professional considerations and concerns of a clinical psychologist or a genetic counselor or a pediatrician are. And so one of the sort of powers of having more disabled practitioners is the ability to speak on the same level to their colleagues about these perspectives. I see this over and over again in my research. It's easy to dismiss an outsider disability self-advocate who doesn't have training in your field in their perspectives and their critiques. It's harder to dismiss one of your colleagues who has this

background and has a lot of the same interests as you in their critiques of the field. And so I think that that is certainly an important part of this...of the value and the support, and the potential for having more disabled clinicians in these fields and many other fields.

I think, also, when you talk to disabled clinicians, what they'll tell you is that, as opposed to being interpreted by patients as somehow biased or somehow incompetent or incapable - and these are the assumptions that are made often by educators who are sort of...or clinicians who are able-bodied and who think, well, maybe these people just can't cut it, or maybe they aren't appropriate for clinical study in the first place - the patients that they have are greatly benefited by having a disabled clinician, by the perspectives that they offer, by the hope, or by the sort of future potential that they offer. If you have a child with developmental disabilities, and a clinician or pediatrician with some sort of developmental disability...seeing them as a pediatrician makes a big difference for a parent and for a child. This would be true of a blind or a deaf clinician and a patient as well. It doesn't have to be a direct concordance either. There's also a lot of questions, uncomfortable questions, that can be answered by a disabled clinician and they can talk about their disability, they can talk about their experiences in a way that can be beneficial for a couple considering a pregnancy, or a person who has recently experienced disability, or the parent of a child with disabilities, that wouldn't be possible for an able-bodied clinician unless they happen to be very closely related to a disabled person. Being able to speak from personal experience is another strength that disabled clinicians bring to the table, and that patients in their experience really appreciate

Emma Wathen: Continuing along this thread about diversifying perspectives in the fields, do you have any wishes for disability futures in genetic counseling, pediatric science, and clinical psychology? I'm particularly interested in the claim that you make in the epilogue of your book that pediatrics is probably in the best position to take the lead in introducing and promoting new disability narratives in the clinic, among patients, and in society. But also they may have the most to lose from significant change. However, please feel free to think beyond pediatrics as well when you think about disability futures that you wish for these fields.

Andrew Hogan: I would certainly like to see more practitioners in these fields be able to feel like it is possible and appropriate, and perhaps even typical to take on a professional role as a disability advocate. And to see disability advocacy as actually part of their professional role as opposed to something on the side, or perhaps something that even sort of challenges or contradicts their professional objective role. In genetic counseling this would involve certainly offering disability perspectives within a genetic counseling session and also opening up space to really have deep conversations about what disability means to a pregnant couple or to an individual in a genetic counseling context. And you know, this could start on an intake form, sort of asking somebody like, what are your feelings about disability? What are your concerns about disability? Instead of trying to cover up this issue or this question entirely. Admittedly it's genetic counselors, more towards the sort of therapeutic counseling aspect, and less towards the just straight, conveying genetic knowledge aspect of their field. I think in pediatrics there's a lot of room for this to potentially happen, for clinicians to see themselves as advocates for disabled people

because, I mean, these people are their patients to begin with. And I think some of the issues and the questions they face are a little bit different, but certainly broadening out what they see their role as.

And, you know, one example of this, one of the parents of a child with disabilities that I focus on in this book, she really sort of highlights the need for pediatricians to play this sort of broader role of care coordination. This is Constance Battle, a pediatrician, though Carl Cooley, who also had a daughter - has a daughter with Down syndrome - made similar arguments that pediatricians need to be playing a broader role in coordinating care both inside and outside of the clinic, involving social work, involving community resources, involving educational accommodations. And so seeing this as fundamental to the role of a pediatrician would be significant. Robert Cooke, way back in the 1960s, argued that every medical student should be assigned a family with disabilities on their first day of medical school, and should follow them and care for them for 4 years, in order to learn more about disability. And he meant this, like, both in the clinic and in the community, in their home, going to their home and getting to know them. And you know, this was a radical idea in the 1960s and it would be a radical idea today if it were to happen. But I think it could fundamentally change the perspective of physicians generally, pediatricians specifically, towards seeing themselves in more of an advocacy role, seeing that as being part of their professional identity and role as opposed to something extra or different, or perhaps conflicting. And the same is true of psychology as well. Psychology is a very diverse field. And so there are certainly openings for, and openings in some subfields of, psychology to take on significant disability advocacy already. But there's also other psychological fields which are much more narrow minded in a medical model sense, if you will, in a biologically oriented sense. And so to see that advocacy perspective be more widespread throughout psychology would certainly be a disability future that I would wish for.

Kelsey Henry: You've given us so much to think about, Andy. This conversation has been so illuminating for me and...like as someone who came into disability history through histories of medicine and science as well, I've also asked a lot of questions about... and like witnessed historical actors asking questions as well about what is the role of the clinician in community? And if we understand...if they understand the human body as their object of study, or their site of intervention, to what extent does the environment and the social world come into their scale of analysis and intervention? And you touch on so many of those questions so beautifully in your book. You've given us a lot to think about, and I know that our listeners will really enjoy this episode. I know you mentioned that you have some other exciting projects on the horizon, and we'd love to hear about them. Do you wanna share anything that you have cooking right now with our listeners?

Andrew Hogan: Sure. Well, coming out of *Disability Dialogues*, and this focus on the need for more disabled clinical professionals, led me to the question, well, what efforts have been made to increase the opportunities, the inclusion, the recruitment of disabled people into health professions? And to study this, I sort of found my way into studying rehabilitation fields, specifically physical therapy and occupational therapy, which you would think would be excellent fields for recruitment of disabled colleagues, disabled students, because they already are very used to working with disabled patients and helping them to achieve their

particular goals and ambitions, right? But what I found is that these fields have done very little to address a desire to recruit more disabled people, or to encourage better, easier, more supportive pathways for disabled students to enter these professions. ~~And well, I-~~ My sort of reaction to this is that I'm in conversation with the people in these fields who are working to make this a reality and to promote this at the same time that I've broadened my perspective to look at questions of recruitment in the context of race and ethnicity as well, and some of the barriers to initiatives to increase diversity, equity, and inclusion for underrepresented racial and ethnic minorities in various health professions. And I think that these two sort of questions speak very well to one another, because a lot of the same barriers come up, a lot of the same concerns about competence and capability and the status of a health profession play a role in willingness to be more open and accessible and supportive and inclusive of minoritized people, whether they be disabled, or from a racial or ethnic minority, or from a gender minority, in various cases. And so my most recent work and recent publications have been looking at minority recruitment initiatives in physical therapy and occupational therapy, and their various successes and failures. The various concerns about, once again, professionalization that get in the way of efforts to become more racially and ethnically diverse.

And I have an article coming out in the next issue of the *Bulletin of the History of Medicine* [available now in the Winter 2023 issue] looking at that. And I've also been looking at education systems and sort of career mobility in these fields, especially physical therapy, but with comparisons to nursing and medicine. So medicine, of course, has been shaped for over a hundred years by the Flexner Report. The Flexner Report intentionally made medicine less accessible, less accessible by class, less accessible by race, and less accessible by gender, and it did so by ~~closing a lot~~ leading to the closure of a lot of medical schools, and by significantly increasing the prerequisite requirements to get into medicine. And what I found is that these efforts to enhance elitism and professionalization and medicine trickle down to other health professions like physical therapy and occupational therapy. And this has led to barriers to becoming more diverse in fields like physical therapy. There is this constant sort of tension between diversity initiatives and professionalization initiatives, and for the most part in the history of these fields, going back to the 1970s, when these two things come into tension with each other the professionalization is always privileged over the diversity questions. And so I just published an article in the journal of *Social Science & Medicine* comparing issues of accessibility and elitism in health professional education, with a focus on Flexner Report, medicine, and its influences on physical therapy, and also with a comparison to nursing, which is, today, one of our most diverse health professions in America, though that's only been the case for the past 20 or 30 years. Nursing was an almost entirely white field as recently as the 1980s.

Kelsey Henry: I'm so excited to hear more about the projects that you have unfolding right now, because I know that they're going to make such necessary contributions to histories of rehabilitative medicine and, like you said, occupational and physical therapy, that are so like understudied in the history of medicine, and these are essential interventions that I'm really excited to see, not only as a historian of medicine, but as a disability historian, because I can see the ways that these projects will continue to contribute, even if it's more aslant, to histories of disability and medicine, because of the fields that you're looking at and the ways

that they're addressing chronic impairments and disabilities in the patient populations that they're looking at. I couldn't be happier to know that these are the projects that that you're working on right now. They're so needed.

Emma Wathen: Yeah, similarly, I already added those to my reading list, and I'm so excited to dig into them and think about them as I'm thinking about how to teach undergraduates about the history of the clinic, the history of these various fields, etc. I think they'll be very interested in that.

Andrew Hogan: Awesome, thank you. They're also both open access, so they will be easy to get.

Kelsey Henry: We love to hear that. Alright, Andy! Well, thank you so much for joining us. We had such a lovely conversation with you. I really enjoyed reading your book, and I'm so excited to release this episode so that other folks can learn more about it, too, and the other projects that you have on the horizon.

Andrew Hogan: All right. Thank you very much. I really appreciated this conversation. And it's a wonderful podcast. I'm really excited to be included in.