

**Disability History Association Podcast**  
**Interview with Nora O’Neill**  
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**Emma Wathen:** Welcome to another episode of the Disability History Association Podcast. I’m Emma Wathen.

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

**Emma Wathen:** And it is our pleasure today to be in conversation with Nora O’Neill. Nora is currently a graduate student in Yale University’s MD PhD program in the History of Science and Medicine. Nora, thank you so much for joining us today.

**Nora O’Neill:** Thanks for having me.

**Emma Wathen:** In the spring of 2023, I had the pleasure of attending Nora’s conference panel at the American Association for the History of Medicine where she gave a fantastic presentation on disability rights and feminist activism in Boston in the 1980s and 1990s. I’m so happy that she’s agreed to share her research on the podcast. But before we get too far into the weeds, Nora, can you first start by telling us about your background as a scholar? When did you first enter the world of disability studies and disability history?

**Nora O’Neill:** Yeah, that’s a great question to start with. So I started studying disability history in college, but my interest in disability started a lot earlier than that. My twin brother has multiple disabilities, both intellectual and physical. So I grew up with him, seeing how both of us experience the world and how the world saw us. We have the privilege of parents who have the resources to advocate for us, whether for education or for medical care, but still my brother faced a lot of challenges in accessing both medical care and education that met his needs and his specific wants.

So I studied history in college and because of my family background and because of my twin brother I got really interested in studying disability history. So I ended up choosing a topic on disability for my undergraduate thesis because I witnessed how much our family had to handle particularly related to ableism. So I finished that thesis way back in 2018, but I always wanted to see it go somewhere. So I ended up presenting on that topic at the conference and I’m excited to talk about it.

**Kelsey Henry:** Thanks for sharing your backstory and your routes and roads into disability history, Nora. I actually have a similar connection. My earliest entry point into thinking about disability is also because I have a sibling, a younger brother, with intellectual and learning disabilities. Yeah, I always, I love hearing about what brings people into the field and how the personal and the professional intertwine over time. So let’s hear more about your work. Your current research centers on the Project on Women and Disability (PWD). Can you tell us a little bit more about the origin story behind the PWD.

**Nora O’Neill:** Definitely. So the Project on Women and Disability was a small advocacy group that got started in Boston. It started as a peer support group for disabled woman in the early 1980s at an independent living center called the Boston Self Help Center. So the

group used peer counseling and consciousness raising to help each other solve problems of access and ableism and also to think together about their identities as both women and as a person with disabilities. The members felt that feminist spaces were not accessible to them due to both physical, cultural, intellectual barriers and that disability rights had been primarily male-dominated and didn't address specific issues related to the intersection of disability and gender, such as reproductive rights. I should note that the PWD primarily used the language of women, so I'll be mirroring their language. As far as I can tell all of the members of the PWD, and most of the people they advocated for, were cis women. We'll get into it, but I did talk to a former member much later down the line and she had said that trans issues were not something that they were aware of. I think the specific wording she used was "it was not on their radar." So yeah, so I'll be mirroring that language.

So the Boston Self Help Center was founded by Irving Zola, who was a disability rights activist and scholar. His partner also just happened to be Judy Norsigian who's the founder of the Boston Woman Health Book Collective, the collective that wrote the famous feminist health book, *Our Bodies, Ourselves*. So there's was literally a marriage of both disability rights and feminism. So Irving Zola actually put the original woman of the PWD in contact with the Collective because they felt that the book *Our Bodies, Ourselves* had not included the perspectives of disabled women. So they ended up collaborating on a chapter specifically on body image, and that chapter appeared in the 1984 version of the health book. After this work, the group officially came together in 1987 and decided to call themselves the Project on Women and Disability.

I should also point out that the first executive director was Marsha Saxton, who was one of the original leaders of the peer support group while she was studying for her PhD. She did eventually leave Boston and spent the rest of her career at the University of California in Berkeley, where she taught disability studies for more than 25 years. She unfortunately passed away in December 2021 but leaves a legacy of many writings and many students who are thinking about disability and gender.

**Kelsey Henry:** Thanks for giving us a little bit more of a foundation for understanding the roots of the PWD. I want us to dig in more to their political platform and the way that they were thinking about representation and intersectionality. So what you've described so far is that the PWD's advocacy was really calling attention to both a lack of disability representation in feminist movements and the lack of women's representation in the disability rights movement. But when I was looking over your slideshow and the paper that you gave, you also mentioned that they struggled to expand their intersectional thinking and action beyond just thinking about women, largely white women, and disability - struggling to engage with black and women of color feminists and LGBT activists. What does the "narrative work" - you use this term "narrative work" and I'm hoping you can flesh that out a little bit for us - of the PWD reveal about these different representational tensions.

**Nora O'Neill:** Yeah, that's an excellent question. So to speak a little bit about how the PWD thought about identity, they specifically called themselves a cross-disability group, meaning that the group welcomed and advocated for people of all different disabilities. And again, like it was particularly interested in advocating for who they called "women with disabilities" and that seems to be primarily cis woman. They did have a few members who identified as lesbian and they do note some tensions among members who identified as women of color. Particularly around a specific campaign that they ran in 1994 that was on reproductive rights.

So this was a campaign that very much focused on sexual health care and reproductive health care for women with disabilities. It involved education workshops for women with disabilities to learn how to advocate for themselves in clinics, educational workshops for doctors, as well as publications about what it would be like to, you know, treat a woman with disabilities, who's pregnant, and also what it would be like to raise a child who had disabilities.

There were tensions that I could see within their meeting minutes, within commentary that some of their education materials had on them, from a few members who felt that the campaign focused too much on "white women's issues," as in thinking about reproductive rights in a very specific, biomedical way. Thinking about access to medical care and not as much thinking about larger issues like access to childcare, access to nutritional food, access to safe places, in addition to not really recognizing the role of racism in the way that reproductive health care had been formed in this country. So that was a major tension that I got a glimpse of in the archives. I wouldn't say that it was like fully fleshed out. For instance, I don't have papers from the members who brought up these concerns, but at the very least I have a sense of that tension. And I will say too, I found very little evidence in the archives that the PWD interacted with other groups that were more focused on LGBTQ issues or on racism. One thing that a member told me was that the group felt that their identity was more focused on disability rights than it was on feminism. Which maybe translated into them focusing a lot more on disability, but again, obviously disability is just one intersection.

**Kelsey Henry:** I actually have a quick follow-up question for you. As you were talking about the extent to which there was and was not overlap with PWD's work and women of color feminist activism and LGBT activism at this time, I can't help but wonder if they did any organizing around HIV/AIDS in this period of time. Which brings up larger questions, I think, about how they were conceptualizing disability, distinguishing between disability and illness, and thinking about stigma. Because I imagine around HIV/AIDS activism that is one point, one issue, that could intersect with disability rights and disability justice activism, and LGBT activism and women of color feminist action. So yeah, I'm curious if you found anything archivally that indicated that they were involved with HIV/AIDS work.

**Nora O'Neill:** Thank you. Yes. That is a very important question considering the time period, that this was the 1980s, and there was so much activism going on around HIV/AIDS. I didn't find any evidence that they were interacting with those groups or even thinking about HIV/AIDS as a disease, as a disability, stigma around the status of having that disease.

Yeah, so I think them not interacting with HIV/AIDS activists and with the general HIV/AIDS movement shows that PWD was focusing on disability and not illness. They were focusing particularly on what I would say a lot of their members had. I do have a sense of, at least a large sort of an overview, of the types of disabilities that the members had based off of conference participation. So they ran a conference in 1995 and in the registration forums, which are all in the archives, they asked if anyone needed any accommodations. A lot of people did offer pretty detailed explanations for what kinds of accommodations they needed. From those registration forms, you can see that a lot of people had physical disabilities and a lot of the writings that they also gathered were related to disabilities that people had had their entire lives.

So they do offer some discussion around disabilities that are acquired later in life. For example, they run a support group for people with paraplegia and specifically for people who, in their young adult lives, had had an accident and all of a sudden were disabled. So it's interesting to think about how, yes, they were a cross-disability organization. Yes, they were thinking about disability in this broad way. And yet, at the same time, there were certain boundaries around who was a PWD member and who they were advocating for.

**Kelsey Henry:** So Nora, you mentioned that the PWD was involved in producing texts and various narratives that were meant to address a lack of representation of women in the disability rights movement and disabled women in the feminist movement. And you refer to this as "narrative work." Can you say a little bit more about the texts that they were involved in and what you mean when you use the term "narrative work"?

**Nora O'Neill:** So their narrative work was a major part of their advocacy. I see the group as having sort of 3 different arms, one of which was education. They hosted a lot of educational workshops around the Boston area. The second one I would think of as sort of offering communication and raising awareness around disability and gender. And then the third is this narrative work. So their narrative work was their efforts to collect stories by disabled women and then share them. And they did this in a number of different ways. One of the major ways was that they published an anthology of stories with the feminist press in 1988. This book was called *With Wings*. So that was published and actually like widely read by many people. It was reviewed by lots of different people, not just in the United States, but elsewhere. And then they also offered writing workshops throughout the Boston area. They had a letter writing campaign where there were letters from people all over the country writing about their experiences with disability. And they also, would publish stories in their newsletter and other forms of publications. They had a couple of different publications throughout the years they were active that were shared among their members. So not necessarily as widely spread as a book that they had published, but newsletters and that sort of thing that were shared with their members.

So they really saw a lot of their advocacy as helping people to sort of figure out a way to share their story. And you know, it's important to note that the PWD was based in Boston, all of these stories appear in English. And they do - it's interesting - they mention that they made recordings of some of these stories, but it also seems that most of them were in print form for the most part. So there's also a question of how disseminated these stories could get, especially across a community of people who maybe had different needs in terms of accessing these stories. What I find really interesting about narrative work is that it can be all encompassing. It offers a chance for writers, and people sharing stories to find common themes and struggles, but also leave space for a diversity of experiences for nuance, for specific things that maybe only one person will ever experience in their life, but maybe someone else shares that experience. So it's a way of sharing stories to find solidarity and also recognizing diversity. And I think the question is, who did they see within their community. As we've talked about, the PWD did struggle to interact with other activists at times and that sort of thing. And I think it's interesting to think about how narrative work can be very powerful, but at the same time the way that it's used can also, in some ways, create boundaries.

**Emma Wathen:** That is fascinating. So I want to go back to what you said a little bit earlier about the origins of the PWD. One of their starting points was that they did not see themselves as being represented within mainstream feminist movements such as the Boston Women's Health Book Collective. So then they subsequently use this term "disability feminism." In what ways is the PWD's disability feminism different from some of the other

feminist health activism that was going on in the 1980s and in the 1990s. What are some issues, for instance, that the PWD is really dedicating their energy to?

**Nora O'Neill:** Marsha Saxton coined the term "disability feminism." Though she does note that perhaps this term existed before across some other writers, but she specifically uses it in 1995 in a publication by The Feminist Press which was this pamphlet that basically asked feminists from across the United States what feminism means to them. So, Saxton's piece appears among a bunch of different people talking about what feminism means to them. So for Saxton it meant disability feminism. And she specifically puts it in contrast to what she considered mainstream feminism at the time, like in the 1980s and 1990s, which for her meant white, straight women's feminism and this idealization of the powerful, strong, independent woman who can have a career, have children, fight sexism, and achieve everything she puts her mind to. So for Saxton, disability feminism centered on moments of *dependence* rather than independence.

So this is a quote that I'll use from her article from 1995: "We know more than most other groups of women, that women can't do everything." So disabled feminists saw these moments as sources of empowerment rather than disempowerment. They called for bodily autonomy and power just as feminist activists did, but also for a recognition of people's dependence on others. And thinking about this dependence not as something to be ashamed of, but as something that everyone experiences and is important for the, you know, the maintenance of a person's individuality as well as individual communities. So this allowed room for a seemingly paradoxical combination of power and dependence that many disabled women maneuvered throughout their lives.

And you know, through this ideology of disability feminism, they very much focused on the idea of access to activist spaces. As mentioned, one of the main issues that the PWD saw with feminism was that they weren't able to access a lot of the places that feminists were gathering, whether because of physical barriers or perhaps because of cultural or intellectual barriers. So for the PWD, they really focused on doing events that didn't involve marching and didn't involve these difficult conversations that tended to go into theory and could be very complicated and that sort of thing. They very much focused on events that were always led by members of the group, so a woman with a disability. But also [these events] were very much led by whoever the audience was. So their advocacy events, their educational workshops, their conferences were, yes, including a leader, but they often involved sort of working with the audience, working with the other members that were there to, you know, help people figure out like what they wanted out of say an educational workshop on sexual health. Yeah, and so again, like all the events being run by members, developing their educational material, and having multiple different versions of the educational material. You know, they were looking to create these kind of spaces that could be opened up to other feminists who maybe were not able to access traditional feminist spaces.

**Emma Wathen:** I have a quick follow up question. Do you think that this focus on dependence, and it sounds like perhaps interdependence as well, is also a way for them to stand apart from the independent rights movement and the disability rights movement.

**Nora O'Neill:** Yeah, that's actually something I haven't fully thought of before. Like I mentioned, they didn't get their start in an independent living center, it was in the Boston Self Help Center. And so they definitely were influenced by the independent living movement. I wonder if Marsha Saxton's focus on dependence, or interdependence, was a response to her concern that disability rights spaces were focused on what she considered

men's issues. One issue that she often brings up that she felt disability rights did not think about at all was child rearing and mothering as a disabled woman. For Saxton as well as for other PWD members who wrote about mothering and offered educational pamphlets about mothering, a lot of them argued that you can't mother on your own. You can't parent on your own and no one can parent on their own. It was not just a specific exclusive experience of disabled parents. So for them, like focusing on, oh, just independent care. Or independent living is not enough. They needed to think about when they needed to be dependent, when they could depend on others, and when others needed to depend on them. And they just felt that disability rights was not doing that.

**Kelsey Henry:** I have a follow up question to Emma's follow-up question. You're giving us so so many fascinating, historically rich stories to work with, Nora. Around this question of dependence and who is in the room, who is involved in PWD activism, when they were thinking about networks of care and advocacy involving care work, to what extent were care attendants and personal health aids involved in PWD? Not only in the care work that they were providing, but actually considered as partners in advocacy and activism.

**Nora O'Neill:** Care attendants and care workers were highly involved in the PWD. I mentioned before the registration forms for their 1995 conference - that asked for whether people needed accommodations and that sort of thing. The registration forms also asked if a care attendant was going to be attending so that they could get the numbers of how many people were going to be there. They also asked if you don't have a care attendant, would you like one for the conference? So they were very aware of the fact that they needed to involve attendants and that, you know, one of the issues was that people weren't able to access that type of care, like having someone who was able to be there for them. So in the conference, this was only a couple of days and obviously wasn't going to solve anyone's care problems, it was sort of showing that they were acknowledging that this was an issue.

They also had workshops that focused on care attendants. So this was meant to be workshops attended by both someone with a disability as well as their care attendants. And it was often centered around communication. So, you know, how do I communicate my needs with you? What happens if there's a conflict? What happens if there's like some issue that I'm upset about and maybe my care attendant doesn't see it and that sort of thing.

I should also point out that they also had workshops for family members and partners of the women with disabilities in PWD. So they recognize that care was not necessarily done by people who were paid to do the work or who volunteered to do the work but also family members, friends, partners. So they really wanted to include them in the fold and they even had specific workshops that were for instance just for partners of people with disabilities, as a space for them to think about, you know, how they navigated moments of dependence as well.

**Kelsey Henry:** Thanks, Nora. We're going to pivot again. I want to talk more about the way that PWD was interacting with some of the major platforms and related sub-movements that fell underneath the heading of feminist health activism in the eighties and nineties. What was the relationship between the PWD and the burgeoning reproductive justice movement in the eighties and nineties? Of course, the term "reproductive justice" wasn't coined until 1994. We can date that back to a group of black women who form the Women of African Descent for Reproductive Justice. But that doesn't mean that the actual labor that went into formulating the reproductive justice movement wasn't already

happening before the, the term itself was coined. So what was the relationship between PWD and the reproductive justice movement in its earliest stages?

**Nora O'Neill:** It's definitely a complicated answer. What I will say is that the PWD was clearly influenced by this kind of activism. They really were looking for an expansion of reproductive rights, thinking about how disability interplayed with politics of abortion, politics of sexual health, of contraception... And yet I did not find anything in the archive that pointed to them talking or interacting with groups in the eighties and the nineties who were really thinking about this. Particularly groups that involved women of color. As I mentioned before, one of the tensions that they brought up was that there were a few women, who identified as women of color in the group, who felt that their reproductive rights campaign - which again they called it "reproductive rights" - that the campaign did not even think about racism in medical spaces or in the politics of abortion.

So it's a complicated answer because I see the connections. They were also calling for a more expansive version of reproductive rights and part of that was including the right to parent and to raise children in a safe and supportive environment, which is a major tenet of reproductive justice. But again, there just wasn't that cross talk. And I think a lot of that just reflects that the PWD was somewhat isolated and probably self-isolating itself as a group of majority white women who weren't thinking with this language and weren't thinking with other people that were thinking about all this stuff at the same time.

So to speak a little bit about their ideas about reproductive rights, they argued that they were a pro-choice group. They very much wanted to move away from pro-life groups that were using disability and pro-life groups that were saying that people who got abortions, you know, we're killing disabled children. They were not interested in that argument. They did not want to limit the right to abortion. They did not want to stop people from choosing abortions. They were, though, uncomfortable with abortions performed due to fetal disability. They cautioned against the pro-choice politics that did not problematize decisions to abort based on disability and they argued that reproductive rights should include the right to raise children, including the right to raise disabled children and have the resources necessary to do so. So it's interesting because they did not want to limit the choice, limit the right to abortion, they focused instead on advocating and talking to people making decisions about pregnancy. So that included parents and included physicians. They offered education material, workshops to visit two physicians on high-risk pregnancies and how to counsel their patients on fetal disability. And they also created support networks of parents with children with disabilities who could connect with individuals who were facing a choice around abortion and keeping a fetus who had a potential disability.

All of this is related to the rise in prenatal technologies at the time, the use of amniocentesis, the use of ultrasound. PWD really saw these as concerning technologies, not because they were offering prenatal diagnosis of disability, but because they felt that disabled women's voices were not being heard in these conversations. They wanted people to be using these technologies, but they also wanted them to be thinking about them and they wanted disabled women to be part of the conversations around, you know, when to use ultrasound, when to make these decisions and that sort of thing. So for them, they had to walk this tricky line of not advocating for laws against abortion, but also thinking about, okay, how do we make this a conversation around abortion and disability without limiting someone's autonomy over their own body?

**Emma Wathen:** So the timeline here is very interesting because you have the reproductive justice movement formally articulating its tenets in 1994, you have the PWD

hosting their conference that you've mentioned before titled "Fierce with Reality" in 1995, which you call the peak of their activism. And then the organization appears to have disbanded shortly after all of these exciting things are happening. So what happened to precipitate this decline?

**Nora O'Neill:** Yeah, the conference happened in 1995 and the group disbanded by the end of that year. It was definitely a question I had as I was going through the archives and so I tried to figure out what exactly was going on. So the conference, "Fierce with Reality" was held at Northeastern. At least a hundred people attended, though probably more, and it was really a space for members, as well as people from across the country to come together to learn about disability, learn about gender. There were educational workshops, there were chances for people to reflect, there were chances for people to write stories, part of their "narrative work." So it seems that the conference was a success, at least based on what the PWD Executive Board said after the conference. They were really excited about how people felt about the conference and what it had done for their community.

I think the major reason that PWD ended in 1995 was financial. They were financially supported by the Boston Women's Health Book Collective, but in 1994 they separated to become their own nonprofit, which is actually something that a lot of their donors had recommended they do to sort of come out from under the Collective's shadow and become their own group, their own nonprofit. However, they faced major money problems after this and a few of members of the executive board who, very few of them had experience with fundraising, ended up leaving because they were so stressed about fundraising that they ended up burning out and not feeling like they could offer their time and energy to the group. So it seems that a lot of it was related to just not being able to support the group anymore financially and not getting enough donors to do so.

The other piece of it was that Marsha Saxton, who - as I mentioned she was the first executive director, she was a major founder of the group - she left for California for a post-doctoral position in 1996. But she had begun to separate from the group in 1994. She'd been frustrated with the amount of work that she had to do for the PWD, especially because they were paying her a very small part time salary and she felt that her work really was a full time job as executive director. So she began to move away from the group in 1994. And right around then is when the rest of the financial problems happen. So I think it's part of that.

The other thing was that PWD pointed to issues of recruitment and their board meeting minutes. They noted that, especially in '95, they were losing members to groups specific to their own disability. So for example, they mentioned a member who left to join the board for nonprofit related to muscular dystrophy, which was the specific disability that that member had. And I would also guess that their reputation as a white woman's group, particularly following their reproductive rights campaign, led to an issue with recruitment across a larger community of people with disabilities, including people who were thinking about other intersections of their identity.

**Emma Wathen:** Yes, that does seem to be a familiar story when it comes to feminist health activism during this time period. Nonetheless, do you see any legacies of the PWD in other social movements? And what can today's disability activists learn from the PWD?

**Nora O'Neill:** The PWD was thinking about the intersection of disability and gender. Around the same time, perhaps probably later, then a lot of other groups are thinking about other intersections with gender. So I really see it as one of one of the groups that



was beginning to articulate what it meant to be a woman, particularly a cis woman. But what it meant to be a woman at that time and how it wasn't just gender and it wasn't just sexism that were shaping their experiences. And what's interesting, too, is that disability feminism was not a rejection of feminism. It was instead calling for an expansion of feminist considerations and of feminist issues. So I really see the PWD as basically making that call for feminism to be expansive, to think beyond the identity of woman, beyond the category of woman, even if PWD at the time was not really thinking in that way. But they were really thinking about how disabled women had not been considered women by feminist, by disability rights activists, by physicians, by people in their communities, and people they were interacting with. So for them they were really calling for an expansion of the identity of woman. And I think if we if we consider other ways in which we can expand what feminism means, what a feminist means, and what feminism can do for people, I think that's part of it.

I will also say it's interesting to have written this thesis mostly in 2017 and then into 2018. The Women's March on the National Mall in January 2017 was happening right around the time I was really beginning to write this thesis. Writing it in a cold Boston dorm room in January was not very fun, but I did it. And so around that time in 2017 a lot of disabled women were writing in the popular press and in blogs about how feminism still wasn't accessible to them. So clearly the problems that the PWD saw with feminism still exist. And I think it's important to think about history as a way to connect activists of today to historical activists and to think about where these stories come from. So for me, writing the PWD story was really about sharing their story with people who are thinking about these issues today. And also showing what PWD failed at, what PWD could have done better, and thinking about how we can expand disability feminism beyond just the specific members that the PWD was made up of.

**Kelsey Henry:** Something that I really love about your work, Nora, is that you're really helping us, giving us the archival materials, and as we'll talk about in a moment, oral history materials, to look at the past's imagined futures, like activist features. And really using history as a resource for contemporary political movements. "What's the unfinished business," I think, is one of the questions that your work helps us ask in relation to feminist health activism and disability justice. And I'm just so excited that we're having this conversation with you. On this topic of a usable past and the kinds of sources that you're exploring, I want to talk more about your source base. On top of looking at the PWDs archival records, you also conducted oral history interviews for this project. Who were some of the people that you talked to? And can you tell us some stories that were surprising or particularly interesting?

**Nora O'Neill:** The advantage of doing history in the 1980s and 1990s is that a lot of your historical actors are still alive and a lot of the people I interviewed were still very much active in disability rights spaces and feminist spaces. So it was fascinating to be able to hear them talk about the PWD as if they were back in those spaces. Back in, you know, the PWD support group and thinking about how it was founded. But also because they were still working in activism, a few of them even working in academia, in disability history and disability studies, they were also thinking about how to place PWD historically and exactly the sort of questions that I was asking as well, like what were the advantages to the PWDs model, what narrative work meant for them, and you know the problems that the PWD had.

So I was able to interview a few people, a few that were both in the PWD and then also in the Boston Women's Health Book Collective. I specifically was able to interact with all of the

executive directors of the PWD, which included, Cindy Blank-Edelman, who I talked to via email, not with an interview, I should be clear. But then also Janna Zwerner, who is the last executive director, as well as Marsha Saxton, who is the last executive director, who again was really who I see as the founder and kind of the heart of the group. And then I was also able to interview Judy Norsigian and Wendy Sandford who were two founders of the Boston Women's Health Book Collective and were very much involved in the PWD's interactions with them and their work on *Our Bodies, Ourselves*.

So I think an exciting thing about oral history is that I did have all of these expansive archival records, I had a lot of information about the group, but there was one question that kept nagging me and we kind of addressed it earlier, which was why did PWD end? Like what happened to it? And again, like I would be able to sort of piece together that there were financial problems, and their leader left, all these sorts of things. But at the same time, there was no direct evidence of, "okay, we're ending the group, the group is over." So I was really excited to be able to talk to both Marsha Saxton and Janna Zwerner about this. And the thing that I found out was that PWD kind of didn't end? It definitely - the board disbanded, they stopped doing their educational workshops, the money ran out. So clearly a piece of it ended. However, Janna Zwerner, who again was the last executive director, told me that people continued to reach out to the PWD for many, many years after 1995. So the group had run a letter referral service, which essentially involved, people writing letters to the PWD and the PWD writing back and offering support, offering possible resources. So it was really cool to see this map of letters coming in from all across the United States and also from outside the US. The PWD was very Boston focused, a lot of their work was in Boston, and yet they were reaching all of these people.

So when the PWD ended, people were still reaching out. Janna Zwerner ended up basically maintaining a mailing address for the PWD. And because she was in disability access spaces, that was sort of her career, she continued answering these letters long after the PWD was over. And, you know, slowly the letters began to dry up and it wasn't until 2010 that she decided, along with Judy Norsigian to donate the archival records. So at that point, I sort of see the PWD is ending. However, clearly the problems that the PWD was working with, the things that they were advocating for, those continued to be problems long after PWD was gone.

**Emma Wathen:** So we've talked a lot about your work on this particular project so far. In addition to doing this excellent history project you've also conducted clinical research at Boston Children's Hospital in the Department of Orthopedic Surgery, focusing on the effects of scoliosis-related disability and invasive scoliosis treatment on patients and their families. So how have your experiences working in the clinic shaped your approach to disability history? And alternatively, how have your experiences as a disability historian shaped your work as a medical practitioner?

**Nora O'Neill:** Yeah, I spent two years between undergrad... So I finished this thesis in 2018. And then spent two years working at Boston Children's doing scoliosis clinical research with the spine surgeons. And then continued on at Yale where I'm doing an MD/PhD program. So I spent two years in the MD program and now I'm in the years of my PhD. My clinical experiences have definitely opened my eyes to the political and social implications of the doctor-patient relationship, of the politics of diagnosis of treatment, and differing meanings of health and healing. At least in the modern US context, I should say, since that is the only place that I've been clinically. And it's interesting because I don't see my clinical experience as particularly advantageous as a historian, in that I know things more or I know things better than historians of medicine and historians of disability who

are not clinicians. Instead, I think that my clinical experience has made me ask questions that maybe I wouldn't have thought of before if I hadn't been in the clinic, if I hadn't been interacting with patients. And also as a medical student I'm beginning to gain this privilege of being a medical professional, of being a clinician. So I think the kinds of questions that I'm asking are different than when I was in undergrad and only doing history and only thinking about history from that perspective. So I think part of it is that I'm even questioning my own privilege and power as a future clinician and thinking about particularly the doctor-patient relationship and what it means for me to be on one side of it.

And vice versa, having history training, is extremely important to me as a clinician. It opens my eyes to the problems and triumphs of our medical system and the historical underpinnings of these politics of diagnosis and treatment and healing. And I think it's really important. I think that every clinician should have at least some historical education, which is why I'm hoping to be a medical historian who is teaching medical professionals in nursing schools and medical schools. So that, you know, people begin to really think about, "Okay, we have this medical system now, but how historically did that come about? And what are different futures for a medical system?" Because it doesn't have to be the way that it is. And I think, too, learning about the history of patient activism, particularly in disability, particularly in gender and all of its intersections, it helps me think about the ways in which patients can advocate for themselves and ways in which I, as a clinician, can help that and maybe get out of the way.

**Kelsey Henry:** I have a small follow-up question - as I'm saying that I'm like, this isn't really a small question (laughs) - it's grounded in experience and it can be anecdotal, but I'm curious. So far, as a medical student, and in the clinical work that you were doing at Boston Children's, I'm curious about if you found good company among other clinicians, even if it was like few and far between, of clinicians who are questioning a medical model of disability. [A model] that is still so firmly grounded in a curative model of disability or, a way of conceptualizing disability as a medical problem that should be cured or eradicated. Yeah, I'm curious about the company that you're keeping and if you've encountered like-minded clinicians not only at the medical student level, but at the full-on like practicing clinician level.

**Nora O'Neill:** I definitely have found like-minded people across sort of all the rankings of medicine. What I will say, as you rightly pointed out, the medical system and medical education is very much focused on cure. And very much focused on action and what we can do to intervene and how we can treat symptoms. And I think, you know, this goes back to sort of our discussion around PWD and them focusing on physical disabilities for the most part, not really thinking about chronic illness. One thing that I've been really interested in lately is thinking about how, within our current medical system, we don't know how to treat chronic illness that doesn't have a clear treatment. We don't know how to handle everyday problems that people are facing if we don't have a cure for them. Basically if we don't know what to do, we just don't do anything. And obviously there are exceptions. There are providers who are thinking about chronic illness and thinking about a more holistic view of health. But overwhelmingly our medical system and medical education is very much focused on cure.

And so the people that I found who are in medicine, who are interested in these questions and interested in being able to treat...Maybe not treat, but to help and to partner with patients who have these kinds of conditions or who have symptoms that don't have a medical explanation, or a biomedical explanation I should say. I find that education is so incredibly important and it's why I have really thought about the ways in which we can

teach about disability and teach about chronic illness that doesn't focus on cure. So I haven't been too, too involved, but I've had a couple of projects related to medical education and really thinking about ways in which we can teach about disability, teach about its social implications, teach about ableism. And the main challenge is that medical school has a lot of curriculum. You have limited time to become a doctor. There's a lot of stuff that you need to learn within this biomedical framework, and I really had to push hard to advocate for space to think about chronic illness, to think about disability in this historical way, in this social way. And there are a lot of people like me, especially a lot of medical students, who are thinking in these ways and want to share it with the rest of their medical student colleagues and with the rest of medicine. And so, yeah, I think it's really something that's being advocated for and we're slowly seeing medical schools and medical systems beginning to think about it too.

**Kelsey Henry:** Nora, what is next for you? I know you said you've done two years of your medical school training. Are you in your second year of the PhD work? Awesome. Okay. So what are you working on right now? What would you like to share with us? What's on the horizon?

**Nora O'Neill:** Yeah, so two years of med school down, one year of the PhD down. So I'm currently in my second year and thinking about dissertation, it's still early, so I'm still trying to figure things out. But a project that I've gotten particularly interested in, especially because of my experience in medical school and being immersed in medical education, is the history of medical education itself. So there's a lot of histories written on medical education prior to 1950, but not a ton written about after. And there were tons of developments that were happening at the time. And not just in the US. I'm really beginning to think of this project as thinking beyond just the US and thinking about medical schools across the world. And yet we don't know a lot about the history of what these developments were.

One thing in particular that I'm interested in looking at is the development of clinical skills teaching. So literally how do you teach empathy for a patient, how do you teach bedside manner? And I find that fascinating, to think about why doctors, and why medical educators realized that this was something that they could teach, defining it as something that they could teach. And then implementing it and seeing if that worked. And though this is going to be focused on medical schools and on curriculum, I do see that these schools and these educators were influenced by health activism at the same time. And so even if I'm not particularly focused on the PWD anymore. I'm really hoping to think about how patient activism at this period or during this period also influence these changes in medical education. And again, it is really a project about thinking into the future - what do we want medical education to look like now? So even though I'm thinking historically, I'm also thinking about how I currently went through medical school and how I want to see medical students taught in the future.

**Emma Wathen:** That sounds like a fantastic and incredibly important project and I hope to hear much more about it in the coming years. Before we end, we always like to ask: Was there anything else that you wanted to mention that we haven't had a chance to talk about?

**Nora O'Neill:** Yeah, I'd like to end on a note of encouragement to people who are in medical professions who are asking questions about history and about what it means to be a healer, what it means to be a medical professional, what it means to be within a medical system that's built on systems of oppression. There is space for that kind of research and

that kind of study and those kinds of questions even if you are a medical professional. And I think it's really important that you do ask those questions. So I see my own work as trying to get clinicians to think about the way the medical system has been set up and the way it is. And I don't want to be alone, I want other people to be doing the same thing as me.

And so yeah, I think it's important to realize that these kinds of questions are important to ask and they're important to ask within the system itself. Like how medical professionals think about themselves, how they think about their patients. All of that is so important. And so if anyone wants to do research in this, wants to think historically, go for it. It is possible.

**Emma Wathen:** And on that encouraging note, Nora, thank you so much for sharing your time with us and good luck on all of your future endeavors.

**Nora O'Neill:** Thanks so much and thanks so much for having me.