

New Directions in C19 Disability Studies: A Roundtable

Welcome to the C19 podcast. I'm Ittai Orr, and I'm speaking with professors Ellen Samuels, Sari Altschuler, and Benjamin Reiss about their work at the intersection of disability and nineteenth century American studies.

Ellen Samuels is associate professor of English at the University of Wisconsin Madison and author of the book *Fantasies of Identification: Disability, Gender, Race*. She is currently working on two new books, *Double Meanings: Representing Conjoined Twins* and *Body of Mine: A Memoir in Genetic Sequence*.

Sari Altschuler is assistant professor of English at Northeastern University and associate director of the Northeastern Humanities Center. Her book, *The Medical Imagination: Literature and Health in the Early United States* was just published by the University of Pennsylvania Press this year.

Benjamin Reiss, Professor of English at Emory University, is the author of three books: *The Showman and the Slave: Race, Death, and Memory in Barnum's America*, *Theaters of Madness: Insane Asylums and Nineteenth-Century American Culture* and most recently, *Wild Nights: How Taming Sleep Created Our Restless World*. He also co-edited *Keywords for Disability Studies* with Rachel Adams and David Serlin in 2015.

Ittai: My main goal for this conversation is to introduce listeners to the exciting insights being developed at the intersection of disability and nineteenth-century American studies. In your

work, each of you has drawn important connections between stories that we are used to hearing about the 19th century, whether it's escaping from slavery, the development of a uniquely American literary renaissance, or the evolution of 19th century science, and concepts that fall under the umbrella of disability today. Disability it seems is actually central to american culture. Let's start there: How has focusing on dis affected the way you understand american culture?

Ellen: Thank you so much. I'm really happy to be here and I think that's really such an important question to ask because disability studies has certainly come a long way since I first began working in it when I was a graduate student, and I started graduate school in the 1990s so you can do the math. I still, you know, I feel like it still has not yet been integrated into 19th century American literary studies as centrally as race or gender have been. And yet I think it absolutely plays a similar role. We wouldn't imagine at this point reading Huck Finn without thinking about race; we don't read Walt Whitman without thinking about sexuality; but we will still for example read Moby Dick without thinking about disability, right? And yet on just the most basic and literal level it is a story about disability right it is a story about Ahab's loss of his leg, and how that shaped his character and his narrative, and as many brilliant Scholars -- Samuel Otter and others -- have pointed out, it is very much a story about bodies, on many different levels. The body of the nation, the body of the whale, the body of the sailors. And when I was encountering disability studies I had the epiphany that most of us have that once you start noticing it as a socially constructed and resonant category of representation in both lived experience, history and literature: that it's

everywhere. It's simply everywhere. You simply cannot talk about American history or culture or literature without noticing it.

Sari: Yeah I just wanted to echo -- I mean I think what Ellen said was really beautiful and I have to say, you know her work has been really influential for me for thinking about disability in the nineteenth century. I think for the sake of the conversation I'm going to play the early 19th century-ist, since my work really starts in the 18th century and so I think my perspective might be a bit different. One of the things that I really struggled with at first when I was coming to disability studies was thinking about the absence of representations of disability in the early period. I was really excited by the questions that disability studies had to ask, but I saw a real lack of representation of disability in early works, and I was puzzled by that and so one of the first things that I did was to try to figure out how and why that was, and then how disability entered literary representation, especially in early US novels. And one of the things that that did for me in terms of thinking about the centrality of disability for American culture was not to say that disability was unimportant for American culture but rather to say that I think in the early especially in the early period we have a real opportunity to see how modern forms of disability came to be, and the kind of struggles, especially the kind of representational struggles and questions that are being worked out from around the 1790s to the war of 1812, and then moving into the kind of representation that Ellen is talking about in terms of works like *Moby Dick* and other works that I think we often associate in disability studies as being representational of the field. And so, that was part of my entry. I have to say that also like Ellen, when I started asking

these questions I didn't know anyone else who was an Early Americanist who was thinking about these questions. So I was both really excited about how much there was to think about and also really daunted by the fact that it wasn't a conversation I saw happening at the conferences that I was going to. I mean I really started thinking about these questions around 2008. One of the things that's been so wonderful is to see how much disability work has been happening at conferences like C19, especially in the last 10 years. I think part of that has to do with what Ellen was saying about how once you start thinking about questions of disability it's kind of hard to stop thinking about them, and you begin to see all of the different ways in which questions about ability and disability are central to American culture.

Ittai: So I wanted to ask, since you mentioned the moment when you were really interested in disability studies' questions for the first time: what are those questions? What drew you to the field in the first place?

Ellen: Yeah, so I was working on this project on literature and medicine and I thought there's this whole field that's really critical of questions that come from a medical perspective and really interrogates that perspective and so I was interested in thinking -- in learning more about what disability studies had to say about the field of medicine. But also, once I started to learn a bit about disability studies, I started to thinking about all kinds of things I hadn't thought about before. One of the first questions that occurred to me was: I remember taking a class on religion in the 19th century and reading a lot about the Second Great Awakening and thinking about what happened to this enormous deaf community that was being formed at the very

same time and how did the Second Great Awakening fit in with- both fit in with because it in fact inspired the schools for the deaf, but also how did it also speak back to questions about the transparency of things like oratory? And I think that as an early americanist, people who work in the early part of the 19th century have spoken quite a bit about the centrality of oratory and the centrality of the spoken word to the transmission of information and knowledge, and nation formation, and I just thought -- I wondered why I had not read anything about the part that the deaf community played in shaping those early ideas.

Ittai: Sticking with this question about how disability plays an important role in the early formation of American culture, let's turn to you Ben.

Ben: Yeah I think the 19th century is a really fascinating period to study in terms of disability history and the development of what we might call disability cultures. And Sari mentioned the article that she wrote--a really powerful article about the relative lack of disability representation in the early American novel-- [which showed that] when you look, by the mid-nineteenth century and certainly going into the late 19th turn of the 20th century disability is really everywhere and I think that that in part corresponds to a new kind of cultural salience for disability and the society at large. And there's a number of factors that are driving the visibility, the cultural preoccupation with different forms of embodiment and enmindment: first you have industrialization and the new kinds of risks to life and limb that were posed by heavy machinery, and then heavy artillery in the civil war, so there was a mass production of maimed bodies or debility on a scale that hadn't really been seen before. Bodies --

different kinds of bodies were circulating and being brought into the open in ways that made disability more visible perhaps on a larger scale than it had been. There's a really interesting new book by Dennis Tyler called *Disabilities of Color* that traces the sort of risks that racialized bodies had for being impaired and the conflation of disability and race across the nineteenth century, but then as a response to the new kind of cultural problems posed by new forms of work and expectations for body management and regularization: specialized institutions, caring for people with different kinds of disability, emerged and these were spaces that were caught up in the moral reform movement and an ethos of cure and recuperation of people who had been judged abnormal in one way or another -- these were also often spaces of cultural expression, and I wrote about this in *Theaters of Ma* that the voices of people who were institutionalized in the 19th century came into broad circulation through journals, through different kinds of life writing, through clinical case studies that circulated in new kinds of journals devoted to different disabled conditions -- so you really had a proliferation of discourse around disability across the 19th c. So, um, there are a lot of social factors in play that both produced an intense awareness of disability and then, that generated discourse and writing around it and we can see that reflected in or soaked up in a lot of the canonical literature of the period.

Ittai: The 19th century seems to be a moment or a whole period of possibility and at the same time a period you can imagine leading to eugenics. So I see both -- I see in all of your work both an embrace of the 19th c cultural sphere as an area of experimentation, slippages, and potential alternate formulations of disability and ability, and at the same time, a period during

which disability came into clearer focus as a category and as an identity, so I'm wondering if that's an accurate description of what you see in the 19th century and how you manage to balance -- all three of you -- how you manage to balance those two sides: both the regulatory, oppressive Foucauldian story on the one hand and a proliferation of ideas and forms on the other hand.

Ben: If I might -- I think that really -- both are true. It really was a period of surveillance and quarantine and regularization, and a kind of curative ideology that ultimately led to the eugenics movement, a sort of purification of the body politic, of sort of defective members, which we can see so powerfully in the literature of naturalism toward the end of the 19th century. But at the same time, it was a period before all that, and I think there's a danger of looking at disability history of the 19th century as a matter of all roads leading toward eugenics. There was some utopian feeling, there were seeds of cross-disability consciousness that came out of the shared experiences of institutionalization, and the development of specialized schools that I think did lay some groundwork for later more politically conscious movements of community building in the latter part of the 20th century. You can look back to the middle of the 19th century and start to see disabled people starting to recognize that they're not alone. That there are others who share their experience even if they have a very different kind of relation to disability, from one another, so I think we have to hold both polarities in mind at once to look at cultural expression from that period.

Sari: I wanted to echo, I think that what Ben is saying is absolutely right. Just to kind of highlight a bit: certainly there is a kind of paternalistic or sometimes sentimental tinge to the work that's being done for individuals with particular kinds of impairments but at the same time, I think that that work makes possible, as Ben's work shows so well, new kinds of community and identification. And I think absolutely there's a danger in saying "and then that's, you know, institutionalization" in a kind of really negative way. I think there are also really positive aspects to you know for example individuals with visual or auditory impairments being brought into new kinds of communities even as those communities are being governed by paternalistic and sometimes damaging assumptions. And one thing that I think is kind of interesting and important to remember is that the reason why people are creating these kinds of communities is because they believe in a radical kind of malleability or human potential and they're looking for -- there's a new attention to people with particular kinds of impairments that absolutely on the one hand can be seen as headed toward eugenics or at the very least a kind of Foucauldian disciplining, but on the other hand, I'm thinking here of someone like Laura Bridgeman who is the first deaf-blind student to be taught to communicate, or at least that's the way that she's touted by Samuel Gridley Howe, who does that work, and there's a lot of interest in helping her develop as a person and thinking about questions of humanity through her, and of course there's an exploitative aspect to that -- I don't want to underplay that, but on the other hand, it made possible a host of technological and communication innovations that at least for a while really enriched her world and made possible things that wouldn't have been possible otherwise. And so, I think your question is

absolutely right, and it's great and really important to think about those tensions and to hold that difficulty together as we undertake the work.

Ellen: Well, I mean, I agree completely with what both Ben and Sari have said and I would add, just to be a little bit of a Foucauldian here, that you know, all of this is also Foucauldian. Like we often focus so much on the disciplinary and the disciplining aspects of Foucault's ideas that we can miss or forget the extent to which he also talked about exactly this process, right? In History of Sexuality part one, when he talks about the repressive hypothesis and he talks about, you know, this new medicalization, pathologization, and disciplining of sexuality, he then points out that there's also the perverse implantation, there is also the discursive generation of naming different kinds of sexual identities such that now people have names for who they are and thus can form communities. You know, once you name the homosexual, then the homosexuals can start getting together and having dance parties! So I think similarly this is the same process in many ways. With disabled people, particularly in different institutions, I mean literal institutions -- asylums, schools for the deaf and blind -- that brought together individuals with impairments who had previously existed within their local communities or not been allowed to exist within their local communities to bring them together. I think one could argue to some extent what some of these institutions did, for both good and ill, is take individual people with impairments, bring them together and make them "disabled people," in the sense that disability is socially constructed, and those communities, even within what we can recognize as the often-repressive and disciplinary context of

institutions, *did* form these communities which then could start developing you know the early disability rights movements like the league for the physically handicapped, which Paul Longmore wrote about. So I think that's what's very difficult, just to jump into the present day in 2018, for us to think about disability justice organizing sometimes because we are at once fighting for the independent living movement, for the right to live outside institutions, and all the ways institutions are dehumanizing and prevent people from being full citizens and full social beings in our world, and yet to also know that to some extent those institutions are what enabled such a thing as a disability rights movement in the first place.

Ittai: I'm really glad that you brought up present-day issues Ellen because my next question is how does this research that's so focused on the 19th century pertain to current and live issues within disability studies, but also to the disability rights movement in general?

Sari: Yeah well I was just going to say that I mean, in general, this is the exciting part of about doing historical work, is that when you reach back -- and I think for me, the late 18th and early 19th centuries are so exciting and generative because -- a lot of these ideas are being worked out and they're kind of inchoate, and the contemporary power of that inchoateness is actually I think in suggesting that the world might have been built differently. We know the way that the world ended up being built, but when you reach back to think about the formation of modern concepts like disability, you see people playing with alternate ideas and kind of grappling with things that end up kind of being codified but were not in that early

period, and I think that there's a lot of political power in realizing that the world once was and could again be built differently. So I think for me that's the real driving force of looking back and thinking about these questions. I've been working on this project with David Weimer at the Harvard libraries, and Ben has been actually a really wonderful advisor on it, and it's a kind of public humanities project that uses disability history to rethink questions in the present. So insofar as it's a good example of the kind of work that reaching back into the past can do for thinking about the present, the project is called "Touch this Page: Making Sense of the Ways we Read" and one of the things we've been interested in doing is thinking about how to reproduce tactility digitally so we're 3D-printing historical materials from blind education in the 19th century and using them to ask general visitors to think about the ways in which all reading is a kind of multisensory act for the most part. So, we often think about reading as being incredibly visual, but how can we use these objects, printed in [raised] roman letters not in braille, how can we use these objects that were designed to be universally accessible to think about reading practices in the past and how we might reimagine our own reading practices and cultures in the present, and the ways in which tactility and auditory aspects of reading in fact are still part of the ways we read but not in ways we recognize so often. I think that's the sort of power and real promise of historical study.

Ben: Yeah I want to go back to something Ellen said at the opening of this conversation, about that revelatory moment many of us have when we realize that we'd been looking at, thinking about, seeing, experiencing, encountering disability all along without quite realizing it in returning to the literature of

the 19th century. And, I think in a way, it's not a there's not a direct application of that startled realization to contemporary advocacy and activist endeavors, but a lot of the best scholarship including I think Ellen's and Sari's on disability in the 19th century is to treat disability as a way of knowing something, a way of experiencing and encountering the world that expands our sense of what's possible. And when we return to even some of these hyper-classic texts of the 19th century, looking through or feeling through or sensing our way through a disabled sensibility on the world, we begin to see disability as a resource. And since we started the conversation with *Moby Dick*, I've been teaching *Moby Dick* this past week to undergraduates and I've thought a lot about disability in *Moby Dick* but I never really noticed the fact that Ahab, when he is walking across the deck of the *Pequot*, has carved little notches to perfectly fit the point of his prosthetic leg, so that when he moves about he's always quite stable. And there's something incredible ingenious about that. My colleague Rosemary Garland Thomson, one of the pioneers and still leading lights of Disability Studies, talks about disability's relation to creativity, that disability often impels innovations in the built environment. You know we can all see this in the kinds of apps that are common on our cell phones that may have been -- you know voice recognition software--that may have been developed for people with low vision or blind people that have become ubiquitous and a tool for all of us. When you look back at writing of the 19th century and think about disabled characters or writers who identify as disabled, you think about them as people who have not just different bodies or different brains, but different ways of knowing or apprehending the world. You really get an

expansion of your sense not only of the period but of human possibility.

Ittai: Thank you so much for that. I think that's really well put. So given this incredible potential, where do you think this field is headed to next? Where has it been and where is it headed?

Ben: Well I've spent a lot of time with institutional records as a way of getting at disability life stories in the 19th century, and these records are you know a massive literature of their own. They're annual reports of asylums and schools, they're professional journals kept by physicians and specialists in different kinds of disability-related caregiving professions, there are journals put out by what today would be called "clients" of these institutions although I hate that word - it feels like such a euphemism -- but as a field, literary studies -- one of the really intriguing possibilities in literary studies today is in quantitative modes of analysis driven by big data, and I think when you start to confront the institutional literature around disability it's almost impossible to get a representative sample across such a huge range of proliferating institutions in the 19th century, and I think that distant reading or big data analyses might be a useful tool to start to identify patterns of discourse and experience that range across these widely disparate institutions and locations of disability. So that's one thing that we just haven't seen yet.

Ellen: And I'm going to both agree and disagree with Ben here. In terms of being on the same page, I think that there's a great deal of work exciting work to be done in the digital humanities, in both 19th century literary studies and disability studies and the two of them together, and one example I've been thinking

about related to my current project but actually a piece of it I published in 2011, on Millie and Christine McCoy, conjoined twins, the first chapter of my book *Double Meanings* I'm working on now, is the way that these images of Millie and Christine McCoy, who were conjoined twins born enslaved in 1851 and exhibited for much of their lives starting from when they were young children, is that that there are these images of them taken without their consent. Those images, because they are not protected by copyright get circulated on the internet in an incredibly proliferative and almost unstoppable way. So you have this 19th-century artifact in which all these issues of race and gender and enslavement and power and disability and enfreakment and medicalization come together that we can't just talk about in the context of 1871. We have to talk about in the context of 2018, when that artifact is all over the google, right? And, thinking about that, about how disability in 19th-century America has become interestingly like reified and capitalized and digitized in the 21st century I think is a really interesting area of inquiry. And then to go in a different direction from Ben, I actually think that there's a great deal to be done still in close reading of these literary works. There is for example I think so much more to be done with Whitman and disability than has been done yet, there's so much more to be done about the figure of the invalid -- Diane Price Herndel has her amazing work about this, but there's so much more that connects it with current discourses about chronic illness and the ways that that's gendered and classed, and the power of diagnosis and what Allison Kaefer calls "undiagnosis." So I do think that for whatever reason since I started working in this, it has been a little bit more of a trickle than a flood in terms of the scholarship being done on disability in 19th-century American literature. It

has certainly increased greatly, like Sari was saying, about people being at conferences doing this work, and I think that's great of course, and I'm excited by Sari and Ben's work and the work being done by others. And yet I still feel like I can be in a conversation with a colleague about, for example, Stephen Crane's *The Monster* -- I was recently in a conversation with a colleague who really just said: "Why do we even need to talk about disability in this text?" like, "Couldn't you do a perfectly cogent reading of *The Monster* that doesn't mention disability?" And so I think there's both this exciting direction and an interesting and productive resistance there that can be the site of some interesting inquiries.

Ittai: So, just before we wrap up, I wonder if you could say a few words about what you're working on now.

Ben: Well one thing that I'm working on now, actually I'm going to turn the tables on our interviewer for a moment, because I had a really wonderful conversation with a young scholar named Ittai Orr at MLA last year who is working on a fabulous project on kind of the intellectual origins and cultural origins of what we today call neurodiversity, and I was just so fascinated by the way you're putting together in your dissertation as I understand it the history of intellectual disability alongside the commitment to kind of intellectual eccentricity in the nineteenth century, and how those things converge in key and rich texts in the 19th century. It was just so fascinating to talk to you about that and it really got me thinking about neurodiversity as a frame for looking backward, an anachronistic frame, obviously. One piece that I'm just starting to sketch out is about the transcendentalist community and a

neurodiverse community and also as a community of care. I'm really struck by the fact that a number of the leading lights of the transcendentalist movement -- Emerson, Margaret Fuller, and if you wanna throw Whitman in that bucket -- all of these powerful writers and intellectual forces had siblings who were intellectually disabled whom they cared for at formative moments of their career, in young adulthood, giving kind of intimate care for them, and that's a story that hasn't really been told about that group, and that -- we think about the transcendentalists as being committed to an ideal of self-reliance, but so many of these figures then moved late in their careers into the role of caregiver. Margaret Fuller and Whitman both became nurses: Fuller in the Italian Revolution and Whitman in the Civil War and I think there is something about that experience -- the intimate experience with caregiving for a disabled family member at this kind of formative period of their lives -- that made these thinkers all in different ways grapple with ideas about autonomy, independence, one's obligation to others, and the ethics of care. So, I'm sort of sketching out something about how key figures in that movement negotiated those tensions in their own writing and their lives.

Ittai: Thanks for the plug ben! That is really a side of the transcendentalists we don't hear much about and could stand to be explored further. So, how about you, Sari, what are your next steps?

Sari: So yeah, I mean I talked a bit about the public humanities aspect of the work I've been doing with the Perkins School for the Blind. That's part of a second book project I've been working on that really is interested in thinking about some of

things we've been talking about. I mean, that project is going to examine a number of different communities and their relationship to canonical works. One aspect of that that I've been working on, I'm just finishing an article about *The Scarlet Letter* and the Perkins School for the Blind, and particularly Hawthorne's relationship to Laura Bridgeman, who I mentioned earlier, and I think there's a kind of secret disability history of *The Scarlet Letter*, that once you realize when Hawthorne was courting his Sofia Hawthorne, who became his wife, when he was courting her, she was constructing a bust of Laura Bridgeman at Perkins and he had a very conflicted relationship to the work she was doing. He was jealous of it. But I started thinking more about the ways the forms of raised print actually - I started thinking about the scarlet letter as a raised print letter on Hester's breast -- and what it might mean to think about the technologies that were being developed for blind and low-vision students in terms of *The Scarlet Letter*. It started opening up a new way of reading the *Scarlet Letter* and thinking of Pearl as a version of Laura Bridgeman, and what the kind of forms of tactile reading that the novel is interested in -- what they do to our readings of the *Scarlet Letter*. So that's an example of the kind of work that I'm interested in doing for this second project.

Ittai: Very Cool! How about you Ellen?

Ellen: I have been working forever. I've definitely been working in crip time, kind of flexible elongated timeline on this book about conjoined twins, *Double Meanings*, primarily about Millie and Christine McCoy. I then move on in the book to look at Ivan and Ivette MacArthur who were born in 1949, also African-American twins, and I kind of trace out these continuities of

enfreakment, racialization, medicalization, and agency and sort of the tension between conjoined twins who are subject to such an intense enfreaking gaze, and then the efforts they take in their lives not so much to escape that gaze but to manipulate it in the ways that best serve their own agency and their own survival. I trace a lot of continuities between the 19th and the 20th and even the 21st century that challenges the often-cited timeline of enfreakment where there were freakshows and then freakshows stopped and then we moved into a different period of medicalized enfreakment, because I really find there really was a great deal of medicalizing enfreakment and in some ways that was the enabling construct for the traditional freakshow, and that today there is still very much different kinds of freakshows happening between the culture that exists on the internet and the existence of reality television and channels like TLC. And of course, other people like Rachel Adams and others have done amazing work that I'm building on. And the other project I've been doing in my crip time way is actually about time. I'm also writing a book called "Sick Time" what am I calling it? *Disability, Chronicity, Futurity*. It is a combination of critical writing about temporality and disability and creative nonfiction about it and I published a piece from this last year in *Disability Studies Quarterly* called "Six Ways of Looking at Crip Time." Those are the two projects I'm most engaged in now and that I hope will be out in the next couple of years.

Ittai: Well all of these projects sound totally fascinating. Thank you all so much for sharing your thoughts and forthcoming work with us. A big thank you to Dan Kubis at the University of Pittsburgh Humanities Center, and Max Glider at the Center for Teaching and Learning for facilitating this recording.

