

## TEACHERS TALK

## “VULNERABILITY AND POWER”: DISABILITY, PEDAGOGY, IDENTITY

*A Conversation with Ellen Samuels*

One of the major contributions of disability studies (DS) is the insight that our bodies change and have changed meaning over time—not just within lifetimes, but more structurally, over decades and centuries. Following the twin leads of Michel Foucault and the Disability Rights movement, scholars in DS have traced the shifting definitions of seemingly self-evident terms like “able-bodied,” “independent,” and “productive,” at the same time reclaiming derogated terms such as “crip” and “mad.”

It’s not surprising, then, how many of the founding figures in the humanities in contemporary DS have been historians and historicizers.<sup>1</sup> Helen Deutsch’s groundbreaking work on early modern concepts of impairment and disability argues that in a culture in which bodies were vulnerable to infections, injury, malnutrition, and prenatal and birth complications, the language for physical and cognitive anomaly was both more granular and more generalized: physically disabled, blind, intellectually disabled, and injured people fell into the same amorphous category as supposed “freaks of nature” (people of unusually large or small stature, conjoined twins, people born without various limbs) and “monsters.” And the eighteenth century distinction between “defect” and “deformities” constitutes a very different vocabulary of bodily difference from the one in place in the twentieth and twenty-first centuries.

At the same time, impairments that would in more recent times be considered wholly disabling—for example, Samuel Johnson’s several disabilities (poor vision, extensive scarring from scrofula, and a neurological condition that resembled Tourette’s syndrome)—were seen as eccentricities or deformities, rather than identifiers of a particular kind of person. Disability scholars have chronicled this dynamic relationship between historical change and embodiment, not least the ways in which marginalized gender, race, and class identities could themselves be categorized as diseases or disabilities. DS has shown the inextricability of US definitions of disability over time from the economics of plantation slavery, the characterization of bourgeois femininity as constitutively diseased, the pathologizing of a range of sexual desires and activities, as well as the historically constructed focus on independence as the measure of citizenship. That is to say, we cannot understand our past, or our present, without looking at how marginal and impaired bodies are imagined to fit into the body politic.

Ellen Samuels is part of the second generation of disability studies academics, a generation that has inherited these insights and built upon them. Trained in the field by established scholars, Samuels claims an intersectional

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<sup>1</sup> For example: Paul K. Longmore, a historian of early America; Rosemarie Garland-Thomson, who was trained in nineteenth century American literature; Tobin Siebers, whose early work explored the relationships between past cultural beliefs and current practices from myth to the Cold War; Douglas C. Baynton, a historian of Deaf culture and the use of American Sign Language from the nineteenth into the twentieth century.

analysis of disability, sexuality, race, gender, and class as foundational to her work. Her 2014 book, *Fantasies of Identification: Disability, Gender, Race*, argues that the American obsession with knowing and fixing bodies into categories—what she calls “biocertification”—is a bedrock element of US modernity. Ranging from literary texts to scientific tracts to visual art, *Fantasies of Identification* takes a panoramic perspective on the place of disability as not just an aspect but a function of American self-fashioning.

I had the opportunity to sit down with Samuels in July, 2015 to talk about disability studies, gaining community, and the vexed place of disability in academia.

SARAH E. CHINN: What do you see as your intervention into the field?

ELLEN SAMUELS: My academic background as an undergraduate was as an English and women’s studies major, and this was in the early 90s before disability studies was present in the US academy in any way. When I returned to graduate school in 1999 at UC Berkeley, I began my PhD in English right when a group of faculty there had received a grant to start a DS program. So I arrived at a very fortuitous time. I had already been doing a little bit of reading and writing in the field before that about my own disabled identity. But arriving not only as they were starting the program, but also at Berkeley, which is the birthplace of the independent living movement and Ed Roberts and all of that—such a vibrant disability community—so I was very lucky to be immersed in that.<sup>2</sup> I very quickly felt, as I think many of us did at that point around fifteen years ago, that there was so much to do in the field; scholars had barely scratched the surface, and so it was very exciting to move into that environment. I also thought about it simultaneously as a disabled person, as a student with a disability, and also as a teacher with a disability. I had already had quite a bit of teaching experience: before I did my PhD I did a Master’s of Fine Arts in creative writing at Cornell University, and I taught there, and then I taught as an adjunct and in private workshops. So when I started my PhD I already identified as a teacher.

Then I was lucky enough to get one of those few jobs in disability studies at the University of Wisconsin. Some classes I teach are disability studies classes—I teach a class called “Gender and Disability” and “Literature and Disability.” And then other classes, like one in body theory, I integrate disability, but it’s not the central focus of the course.

SEC: For me, at least, what’s so useful about DS is a sort of ethics that you can bring with you. It’s like queer studies; it positions you in relation to normativity in a totally different way, so that even if you’re not teaching DS, it’s always in your mind about how are bodies represented, how are bodies functioning, how is functionality represented, what does it mean to be normal? All those things that I initially came to through queer theory opened up in this huge way for me in DS, and I think that might explain as well why there’s been such a fruitful rela-

2 Edward Roberts (1939–1995) was a Berkeley student who used a wheelchair and was a leading organizer of disability rights and independent living activism in the San Francisco Bay Area. He was also the first disabled person to serve as director of California’s Department of Vocational Rehabilitation.

tionship in talking about sexuality, talking about gender, and talking about disability. I'm wondering, particularly with a women's studies background, if you could say something about those relationships?

ES: I think that some of the most important figures for me in developing my queer and feminist consciousness and practice, like Audre Lorde, are also figures of disability and bodily difference. Lorde famously talked about growing up as a fat, black, half-blind girl. I teach her *Cancer Journals* in my disability class, and I find that to be such a productive way to think about the intersection of these issues. And when Lorde was talking about the mythical norm, then Rosemarie Garland-Thomson comes along in the 1990s and talks about the normate, you really see that there's such a fruitful relationship there in the critique of the normal. Another way I see them relating is the investment that the students have. It's not only that they're such a self-selected group, they have a lot to say, they have a lot of feelings, but also how the class relates and is so closely connected to their bodies and their identities. That is absolutely true of DS as well. In the introductory class I teach, Gender Studies 101, students are profoundly affected when I talk about bodies, body image, how our culture teaches people who are assigned and identify as female to hate our bodies. I run into students years later who talk about how the class changed their lives, what a huge effect it had; I never run into a student who says "I took your intro to American literature and it changed my life!" [Laughter all around].

I do have wonderful students in my English classes. But it's that personal connection that's transformation and empowerment [that's less obvious in a literature class]. And I see that in DS as well. That's why, when I'm teaching a DS class, I come out as disabled on the first day, since it's not immediately obvious. And I feel that's really important because for students who have some kind of personal relationship to disability in one way or another –

SEC: which, in my experience teaching those classes, turns out to be almost all of them –

ES: Yes, it does.

SEC: It comes out bit by bit, week by week, but it happens. I just taught an Introduction to Disability Theory last year, and in the beginning, there were only a couple of students who actively identified as disabled. By the end, all of them, pretty much, had identified either as disabled, or having a disabled person in their life.

ES: I do the same thing. On the first day, they get into pairs and discuss, "what's your experience with disability?" Some of them say, "none." By the end of the semester, all of them recognize that they do. Going on that journey with them, it feels very important for me to be upfront about the fact that I have a disability, that I identify as dis-

abled, because that's so rare for students to see a faculty member with a disability. [Disclosing my disability] foregrounds that someone can be disabled without being in a wheelchair or being obviously disabled in certain ways. I was struck, this past semester when I taught my Literature and Disability class, how many more of the students, on the very first day, introduced themselves as having a disabled identity. The reason is that I now have for the past couple of years had colleagues teaching DS, so students have already taken classes. It really gives you a sense of how having a critical mass of people working with disability issues on a campus can affect the classroom, so you're not just doing intro every single time. Students are already there.

SEC: And you have a shared vocabulary. It's so important that they're not coming to you to pick up the language—they're already conversant in it, and that can be a foundation for conversation itself.

I'm wondering, since you made that comparison between disability narratives teaching on the one hand, and the first half of the American survey, for example, on the other, do you find pedagogically that you're working differently in a class that's speaking about more general issues of identity, but more specifically disability identity than you do if you're teaching, say, nineteenth century American literature?

ES: In any literature class, I'm going in with an assumption that our primary, as they say today, "learning outcomes" are specific to that discipline. So the learning outcomes for a literature class will always include things like close reading skills, historical knowledge, and so on. I'm grounded so deeply in literature both as a writer and as a literary scholar, that I never want to abandon the fact that this is literature, and treating a literary text like it's just a piece of information about an issue, if you know what I mean.

SEC: I know exactly what you mean — there's an aesthetics, there's a reading practice that you bring to it, so even if you are reading a sermon or a speech, you recognize that it's a rhetorical entity. It's not completely artless: the person did this on purpose, and we have to figure out what's going on.

ES: Exactly. Whereas when I'm teaching in a non-literary DS context, I'm much less concerned about that. I'll still use poetry—one of my long-standing rules is that I use poetry in every single class. If I'm teaching theory, I'll use poetry. In DS I'm less concerned with "let's spend some time with the language of this poem, with the form of this poem..." and more with "what's your reaction to this poem, what sense does it give you of the author's relationship to their disability?" Similarly, in a primarily gender and women's studies, queer studies classroom, [gender or queer identities] will be first and foremost in the class. I will find ways of making it never "just" gender, "just" sexuality, but always some intersectional context that always includes disability.

SEC: Since you said in your disability classes, you always come out as disabled on the first day, how do you experience your disabled self in a non-disability-oriented classroom? Obviously, the political mandate to be out feels different, because that's not what the class is about, but then you're dealing with the assumption of able-bodiedness, the assumption of heteronormativity, all that stuff that's not explicitly the content of the class is going to come up. You're being seen in a very different way—not as someone identified with the material, or as someone imagined to empathize with the material. That's a very different position for you to be in [compared to teaching in the DS classroom]. So do you feel yourself making those shifts pedagogically?

ES: Absolutely. Being an instructor in a classroom is a vulnerable position as well as a powerful position. That dynamic gets tweaked in terms of the identity positions of the teacher and the identity positions of the students. Because in my DS classrooms I start on the first day with an intensive crash course in “what do we mean by disability?” it would seem very disingenuous for me to conceal my own disability identity. Whereas in other classrooms—and I'm the same with my queer identity—it's actually sometimes pedagogically useful to not necessarily disclose, to keep them guessing in certain ways, particularly in the women's and gender studies classroom. I remember from when I was an undergraduate, the focus, the investment that students have in their professor's identity, the professor's body and sexuality, is so intense—so I like to play with it. If I am having a day in which my disability is more visible, when I'm using my cane or I'm limping, I won't necessarily address that in class, because I find that makes students uncomfortable; it breaks down this fourth wall, they don't want to think of their professors as vulnerable. On the other hand, one of the ways that my disability most evokes narration is my rings.<sup>3</sup> My ring splints are very noticeable —

<sup>3</sup> Samuels wears silver-toned ring splints that wrap around the fingers of both hands.

SEC: — and cool!

ES: — and cool! And I get a lot of compliments and a lot of questions about them. I always tell this story about my large lecture class. I don't get to interact with the students very much, the TAs have the discussion sections, I'm just up there giving my lectures. I love it, but you really miss that interaction and there is an extra boundary. One day a student stayed after class and said “I have a question.” So I'm thinking “oh, you have a question about this wonderful lecture that I just gave about commodification in culture and gender,” and she said, “what are your rings!? Where are they from?” That is a question that I get every time I leave my house—from cashiers, random people. But I was so floored that the student stayed after class to ask me. So I gave her my standard answer: these are actually called silver ring splints, they're medical jewelry. I have a joint condition — the joints in my hands are weak and they make them stronger. Then people often apologize: “oh, I didn't

realize, I thought they were just jewelry.” And I say “it’s ok, a lot of people think that.”

I had two TAs at the time, both wonderful grad students, I was on both of their dissertation committees, I thought that I knew them pretty well. I was telling them about the student with the question, and I discovered that neither of them knew what my rings were for. They had never raised it, but they had discussed it *extensively*! They began saying things like, “oh, I thought your rings were some kind of vampire jewelry” and “I thought your rings were a BDSM thing.” We’re halfway through the semester and my TAs have constructed a narrative about my rings that they didn’t connect to my disability identity.

I teach a wonderful class called “The Body in Theory and Practice.” It’s always jam-packed full of students, in part because it satisfies the theory requirement for our women’s and gender studies majors, but also because our students love to talk about their bodies. It’s a very intense class—the first three weeks it’s all Foucault all the time. I ask all of them to give a very short presentation. There are three options for the presentation, which range from personal disclosure to no personal disclosure: bring in a cultural artifact related to the body in some way, and talk about it; tell a story about your body in some way; or do some kind of bodily performance, like dance. When I give the assignment, I use my rings to demonstrate these options. I say, “my rings are a cultural artifact: they are jewelry that also serves a medical purpose.” Then for the story I say, “I have a connective tissue disorder and that is why I wear these rings. Before I got them, my hands were so painful and so weak that I couldn’t type. These rings are a profoundly enabling device for me, but they’re also really cool, and so I get a lot of compliments on them.” And then I show them what my hands do without the rings. I show them on my pinky – I’m not supposed to do things with my hands without them, but my top joint on my pinky is a good illustration [she bends the top joint back towards her finger to about 90 degrees]. So then I say to them “look, I just did all three of the forms of presentation for you.” I’ve taught this class several times over the years. So that has become my ritualized way of how I come out, how I disclose my disability.

The students, in their presentations, sometimes make very profound disclosures, and other times conduct very smart, funny discussions of cultural artifacts. In one student presentation about marching bands and the panopticon, the student described being on the field practicing their marching band routines while the band director actually stands in this tower and watches them!

SEC: Do you think that there are things that disability studies brings to pedagogy that we wouldn’t otherwise have?

ES: Yes, in the same way that I think that gender and women’s studies brings something to pedagogy, and queer studies brings something to pedagogy, and critical race studies brings something to pedagogy. But

what I think is interesting about DS and maybe a little different from those other identity-based fields or areas is that most of the time students have very limited and very stereotypical understandings of disability, as I'm sure you've experienced. To intervene in those, and come up against really significant resistance, requires us to be really creative in our pedagogical strategies. I've had the experience, and I've talked to other colleagues in DS who've had the experience, of teaching a class you're doing nothing but tearing down the idea of the Heroic Overcomer and the Inspirational Cripple, and then you get a final paper in which students are using those figures. And you think, "have I failed? How did I fail? What did I do wrong?" That brings me back to thinking about [Paolo Freire's] *Pedagogy of the Oppressed*, and the banking model of knowledge versus the model in which you are providing critical tools. I can tell my students from dusk till dawn about these stereotypes and about the importance of challenging them, I can fill their minds up, and I can probably give them a test and they could tell me what the Heroic Overcomer is. But what's much more challenging, and what I think is always going to be incomplete and is always going to be an ongoing process, is giving them tools to get outside of those models of disability.

SEC: Earlier, you talked about the whole learning objectives model, and that's something that's happening all over, especially in public education (and in an appalling way in Wisconsin!). One thing that in the humanities we're finding really hard to communicate is that this is not just a one-time thing. You don't just teach a class and then the students just suddenly understand—particularly a class that is theoretically grounded, dealing with ideas that students may not have ever encountered before. It's not like they took Chemistry 1, and then they took Chemistry 2, and then they took Chemistry 3. Rather, it's building, building, building over time. Students may never have thought about the idea that talking about someone who overcame their loss of a leg to run a marathon is not the most useful way of thinking about disability, and might actually be deleterious. Because in the world in which we live it's the best way of talking about disability!! We've almost normalized that with gender and race: we can say "this is how race operates in our culture. It's not the same everywhere, it's different given the different historical moments, it's always emerging, and yet white supremacy is always the lodestone." And you've got to keep saying that again and again and again. Can you track that in a meaningful way?

ES: Can you measure it?

SEC: Not really. And it might sink in five years later. You're taking a second-year undergraduate who has never, never thought about this stuff, and somehow you have to say that by the end of week fourteen or fifteen, they're going to have this chunk of understanding about the

social model of disability, about compulsory ablebodiedness. That works, as you say, in the banking model: I'm going to fill them full of theoretical insight and then they're going to somehow be able to spew it back out. But that's not really how insight operates.

ES: There are times when I don't totally throw the banking model out. There's certain information, there are certain facts, certain histories, that are important for them to know. Over and over again, I teach students: there was a disability rights movement, there were protests, there's Section 504, there are people crawling up the steps of the US Capitol.<sup>4</sup> Especially in Women's and Gender Studies classes, students are amazed—they ask “why did I never learn about this?”

<sup>4</sup> Section 504 of the 1973 federal Rehabilitation Act was a precursor to the 1995 Americans with Disabilities Act. It stated that people with disabilities cannot be excluded from participation in, denied benefits from, or be subjected to discrimination by any agency receiving federal funding. This was especially important for K-12 schools, colleges, and universities, as well as public facilities such as airports, and was a direct result of work by disability activists in the 1960s and early 1970s.

SEC: Because they feel so politicized...

ES:...and they feel empowered, and yet. I realized that very early on, I needed to give them a little history of where racism came from in the US. We are in a US classroom in 2015, so I'm going to talk to you about conquest and colonialism, and give you the very specific history of racializing in the US. Their sense of time is so compressed. They were born in the 1990s, and they haven't gotten that history.

In part it's the public schools, but it's also their personal experiences. When they introduce themselves, they'll just say, “I come from a small town in Wisconsin, you won't have heard of it.” They don't even say the name. Almost all of my African American students come from Milwaukee. But almost all students in the US are coming to us with ignorance of the disability rights movement. They're not getting that information except in very rare and unusual instances. Yet they all have this tremendous capability to take that history and fit it into what they know about the civil rights movement, or the women's movement, or the LGBT/queer rights movement. So then they are more likely to say “how can I possibly keep my image of the tragic victim or the overcomer in my brain when I also have this politically radical movement in there too?”

SEC: Exactly. If you think about the independent living movement in the same way that you think about Stonewall, you can't really think about poor cripples anymore. It just doesn't work that way. If you want to see those two things as a) happening historically at around the same time and b) being motivated by the same set of political commitments, you're right—you can't have Tiny Tim from “A Christmas Carol” in your brain anymore.

ES: And I think about my own pathway as identifying not only as disabled but also as a disability scholar and a disability activist, and the importance of knowing what a long journey it is. When I went to my first disability conference in the late 1990s, I was not in school at the time. I was living in Boston, and I was struggling very hard. I had gone

straight from undergrad to graduate school, and it was while I was at Cornell that my various vulnerabilities really coalesced and truly disabled me. I was 23, 24 and I was hit with the fact that I was not going to be able to work a 9-5 job to support myself ever again. I moved to Boston, I was teaching as an adjunct, I was going to doctors a lot, I was trying to figure out what to do. And I found a flyer at the school where I was teaching, for this conference at Southern Connecticut State University. They do a feminist conference every year with a theme, and they decided to have disability as their theme. They called their conference "Fulfilling Possibilities: Women and Girls with Disabilities." I sent in a proposal and it was accepted and I went to the conference. I know that there were a lot of problems with the conference, tons of access problems, tons of issues that I was at that time mostly unaware of.

But the experience of being around all these disabled people made me recognize my own stereotypes and assumptions and fears about disabled people. I remember looking at a person next to me in a wheelchair, and she had a sticker on it that said "Piss on Pity." It blew my mind. I was like, "what? You mean that this person that I've been taught to fear and pity my whole life doesn't want my pity, has an attitude, is actually like the queer radical activists that I've been marching in the streets with for many years?" I met Alison Kafer at that conference.<sup>5</sup> I met Corbett O'Toole.<sup>6</sup> It was the beginning of my entrée into a community. I can't overemphasize how important that was to me as a young person who was losing so much at that point in my life to realize that I was also gaining.

SEC: Alison also talks about that. She says that disability studies saved her life. There is something about being able to understand your new place in the world, which is really what it is: "I am not the person that I was four years ago and I've had no framework to understand myself, and now I'm having a framework that's familiar to me as someone who thinks about political and cultural theory." It's that existential part. But it also then allows you to engage with the world, to have a vocabulary to speak to other people about yourself that isn't rooted in the fucked up ideas of pity or overcoming. Because if that's the only way you get to think about yourself, that is pretty depressing.

ES: It's so depressing. And I would say that just as the message to female-identified people is that your looks are all that matter, but your looks aren't good enough, is not only profoundly damaging but a tactic to keep us from uniting and fighting for all the things that matter, it's the same way with the messages about disability, and the system of disability services and support that's so profoundly dehumanizing and difficult. It's really a full-time job, and often a fruitless one, to try to navigate the system of disability benefits and support, and that's part of what I was experiencing at that part of my life as well. I had a lot of privilege, I was getting a lot of support at the time from my father, which was enabling

5 Alison Kafer is a queer disability scholar and activist in the Feminist Studies Department at Southwestern University. She is the author of *Feminist, Queer, Crip*.

6 Corbett O'Toole is a lesbian and feminist activist who has written widely on disabled lesbian issues. She was a founder of the National Disabled Women's Educational Equity Project, as well as an organizer of the Disabled Women's Symposium leading up to the Fourth World Conference on Women in Beijing in 1995.

me to work only part-time, but that was not going to go on forever. I had not worked enough to be eligible for Social Security, having been in school continuously. I ran up against the fact that there is no safety net for me. One of the big reasons that I decided to return to academia and get my PhD was that even though I love teaching, I couldn't really get a full-time job with my MFA. I said, this is the only thing I can do to support myself and be independent, and make my own hours, and get the accommodations I needed. I acknowledged that I had a lot of privilege going into that situation—my parents were both college professors, I had an elite education that enabled me to get into a PhD program that would support me. But at the same time I found myself in a profoundly unjust situation because I had this genetic condition and developed all of these physical disabilities and was scared for my survival.

SEC: So to have language with which to talk about that, people to talk about it with, and an environment in which that conversation can happen, in which the basic stuff is already dealt with, makes a huge difference.

ES: Right. I talk to graduate students a lot about disability disclosure on the academic job market. It's risky, and it's complicated, and I say that in some ways it was easier for me because I was "professionally disabled." I had published in the field of DS. Simply being out there as disabled, being very clear about my access and my accommodation needs, has not cleared the path. I still fight that fight all the time. It was extraordinary how when I would give the exact same information about what I could or couldn't do to different places for campus visits, I got such different responses. Some just really had no idea about which buildings on campus were accessible. They'd bring me to a building and say "we're going to climb these three flights of stairs," and I did. It was a terrible decision on my part. I was in terrible respiratory distress at the top and a meeting with this dean became horrible and stressful. These are the ways we push ourselves to be the Supercrip.

SEC: Because what are you going to do? Stand at the bottom of the stairs? If there were ever a symbol for inaccessibility!

ES: Yes, I was standing in the foyer—there wasn't even a lobby, it was just a foyer—and it was the official "go and talk to the dean" meeting, and I was just a graduate student, so I didn't feel like I could say, "I'm sorry, she needs to come downstairs." And the dean is watching me gasping in her office and saying "I could have come downstairs!" So I try to counsel graduate students on the market as much as I can about how to handle these situations. But at the same time, there are always going to be snafus.

That happens in the classroom too. One semester I was scheduled in a classroom that wasn't a media room, so I couldn't do Powerpoint and other technology, which was of course the semester that I really badly dislocated my shoulder, which happens regularly. I was in a

shoulder immobilizer, so I couldn't write on the board. And that was an American literature class – it had nothing to do with disability, but I had to profoundly perform my disability for them in so many ways that made me feel really vulnerable and frustrated with how these journeys are never over, these negotiations are never won. You're redoing it every time.

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