

How You Tell the Story: In Search of Complex Disabled Narratives

Lilith A. Logan Siegel

A spring evening of my senior year at Smith College found me in an aged and dusty lecture hall with much of the rest of my class. The ways in which I was different from those around me will occupy much of this essay. But in this I was utterly similar: I needed a job. I knew already that I hoped to go to law school, but an emotionally and physically strenuous senior year had delayed the process. Hence my somewhat belated presence at a seminar titled “Planning the Next Step.” Incidentally, I was sitting in the first row. Over the years, people have interpreted my tendency to sit in the front row as a sign of dedication. In fact, most lecture halls, even newly built ones, have steps up to the back, so the first row makes the most sense for my mobility needs, and minimizes my time away from the class should I have to use the bathroom. *Planning the next step*, indeed. Perhaps there is an analysis to be done about the way that this seating made me think about myself, but that is only kind of the subject of this essay. More central was a hastily scribbled note from that night that I rediscovered later, while cleaning out my papers in preparation to move some 3,000 miles to Berkeley for law school. On a piece of notebook paper, surrounded by childish hearts and asterisks, I had written: *Find a network*.

When I wrote the note during my final year of college, I already had a tight cohort of deeply supportive friends and professors. Indeed, they were among the first people to see real intellectual value in my disabled way of being and to give me the tools and language to express that value. But none of them could give me the information that I felt sure I needed about how to get through law school, let alone the legal profession, with an intractable and dynamic disability. Through some combination of elite schooling, personality, and interactions with an admirably hard-charging disability rights movement, I had internalized the fear that there was only one correct way to be a disabled lawyer: utterly determined, full of pride, a happy warrior. I was terrified that opening up about my fears would limit my possibilities. Or worse, were I to disclose the grief that the everyday and permanent impairment caused me, then

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as now, I would confirm the worst, most simplistic stereotypes that I assumed everyone had about disability—that it was a tragedy, relegating sufferers to a life of misery. That is not the story I was hoping to tell.

It would be five years before I would learn about “stereotype threat,” a fear of confirming negative stereotypes about one’s identity. A 2L seminar on “Implicit Bias and the Law” taught me that this is a well-documented psychological phenomenon experienced by many marginalized students at elite institutions—one that impedes academic success.¹ When I learned that, I wrote *Oh good, it’s my brain’s fault, like all manner of nonsense!* in the margins of the PDF I was reading. I wish I had not been so convinced of my own alienation and singularity.

But as it was, I returned to my dorm that night after the career presentation, bursting with pragmatism and naiveté and blithely typed the name of my disability and my professional ambition into Google: “cerebral palsy” and “law professor.” What I found when I pressed “enter” were thousands of entries about medical malpractice law, information about suing for damages in response to a child being born with cerebral palsy as well as information about how to apply for disability-related benefits. Not a single disabled adult, not a single disabled professional. I know now that there are disabled law professors, but none of them came up in my search.

Surely to have found nothing would have been better. It would have alerted me that I was operating against a clean slate—a demanding but freeing way to be in the world. What I learned then, and understand ever more fully now, is that “disability” is ever present in the discourses and pragmatics of the law but seldom in a way that casts disabled people as empowered. What’s more, this oversimplified and pathologizing framing has material consequences, both for disabled people studying law and for those seeking to use law to advance equity for disabled people, not to mention for the people seeking help from the law. Looking at these results made me feel simultaneously inundated and empty. They represented what I can only assume will be a lifelong process of searching for resonant, nuanced disabled stories to guide my body, mind, and path forward in a difficult profession.

In this essay I will reflect on the way that I found complex disabled stories in two forums that shaped my law school trajectory: the classroom and the clinic. The settings, respectively, showcase me as a disabled student and me, with trepidation, turning outward to use a disability lens in the service of others. In so doing, I will suggest ways that disability discourse could have been elevated

1 For more on stereotype threat, see, e.g., CLAUDE M. STEELE, WHISTLING VIVALDI: HOW STEREOTYPES AFFECT US AND WHAT WE CAN DO (2010). For disability-specific applications, see Alison L. May & C. Addison Stone, *An Initial Investigation into the Role of Stereotype Threat in the Test Performance of College Students with Learning Disabilities*, 27 J. POSTSECONDARY EDUC. & DISABILITY 89 (2014) (discussing impact of stereotype threat on disabled students); Arielle M. Silverman & Geoffrey L. Cohen, *Stereotypes as Stumbling-blocks: How Coping with Stereotype Threat Affects Life Outcomes for People with Physical Disabilities*, 40 PERSONALITY & SOC. PSYCHOL. BULL. 1330 (2014) (suggesting that stereotypes undermine life outcomes for people with physical disabilities).

in those spaces, to my benefit and that of all involved. And I will tell the story the only way I can, with cerebral palsy, depression, and an anxiety disorder, ensconced safely, but sadly, at home in the middle of a global pandemic.² I will edit this essay many times trying to make it more linear, or perhaps circular. I will struggle to encapsulate myself in the strictures of brevity, structure and flow that I have been taught characterize good legal writing. I will fail, and, in so failing, tell a story.

But I want to be careful in the telling not to fall into my own simple disabled narrative. Very often the fact that I have graduated from law school is seen as a sign that I have overcome my disability through individual willpower, having fully embraced the role of disabled advocate. That is not the story I am telling. My disability remains very much a part of my life, and always will be. More importantly, though, to attribute my journey to individual willpower is to suggest that those who have not “made it” are less worthy, all the while erasing the many ways that whiteness, socioeconomic comfort, and resources facilitate my success. This is a dangerous game, with very real consequences for more marginalized disabled people. What’s more, individualizing success in this way makes it all too easy for institutions and people to escape introspection about the systemic reasons for the “success” or “failure” of disabled students. One thing I know for certain is that how you tell the story—about disability, about the law, about education, about those you seek to help, and about yourself—matters immensely.

I. Disabling: A Syllabus

If you had asked me before running that Google search, and indeed before going to law school, why people were uncomfortable talking about disability in law school classrooms, I would have said that it was because they did not do it enough. And, indeed, I continue to attend “social justice” and “diversity” events that do not mention disability. But the search results suggest, and my time in law school confirms, that the law talks of disability all the time, just not in a way that centers people with disabilities, and too often in a way that frames disability as (only) a problem to be solved. Again, how you tell the story matters.

I saw disability in the torts case I read during my second week of law school, in which a footnote told me that the plaintiff was institutionalized, but that fact was not mentioned elsewhere in the case. I saw it in the question of

2 As I think about what it means to have hope about disabled futures in the midst of this pandemic, I am indebted to Leah Lakshmi Piepzna-Samarasinha’s Society for Disability Studies keynote “*Every Time is Crip Time Now: Wild Disability Justice Pandemic Futures.*” See SDS 2020 Virtual Keynote: Leah Lakshmi Piepzna-Samarasinha, YOUTUBE (Sept. 22, 2020), https://www.youtube.com/watch?time_continue=1&v=dy6y2MgSHzo&feature=emb_logo&fbclid=IwAR3Bk_GQJaVc4vuP3ld4iRIB6VohPDK1n1jrZuRhkUbIPvn_iCPQKWgdaVU. More broadly, I know that my own thinking as a white, queer disabled lawyer, including my emphasis on the importance of narrative, has been profoundly shaped by the labor of disabled QTBIPOC thinkers, actors and writers. I am profoundly grateful, and will always try to pay it forward in every way I can.

capacity to enter a contract, and competency to stand trial or to raise a child. I saw it in questions of guilt and innocence and intent. And as illustrated starkly above, I saw it in how, why, and to whom the law offers remedies. It was there in the California rule of professional conduct that stated that a lawyer must withdraw from representation if “the lawyer’s mental or physical condition renders it unreasonably difficult to carry out the representation effectively.”³ In the margin next to that rule, I wrote: *So what are they expecting of me? It’s like I’m not even here.* I saw it in the assumption that disability discrimination was subject only to rational basis review. I don’t recall debating in law school whether disability was an immutable characteristic, although, to be sure, I have had that debate with myself. Lived it, even.

Each time I noticed these absences in a class, I would have what became a well-scripted debate with myself about whether to speak up. These were wrenching decisions. I wanted more than anything to be seen as personally and intellectually complicated. And I resisted the simplified narrative of “disabled woman talking about disabled things.” Most often the silence became personally and intellectually untenable, and I said something. But it never became easy. I was not always looking for disabled stories in the law, but they were there nonetheless.

Because I have been open about these experiences, I am often asked by professors and mentors how they could do more to incorporate disability into their own thinking, advocacy, and teaching. I used to respond to this request by, essentially, suggesting a case that could be added to a syllabus that includes a disabled party or embodies a significant development in disability law. With the benefit of hindsight, I have begun to rethink this strategy. Rewriting a syllabus to center disability is great if one has the expertise, time, desire, and institutional resources to do so. But I believe that significant good can be done by naming the ways that disability, in concert with racism and other forms of oppression, shapes whatever syllabi are already being taught. Naming the disability that is already there, as opposed to being additive, is one way that professors and advocates can answer for the way that disability has been ignored in the past. This framing also shifts the onus away from individual students to raise issues, allowing them in some cases to preserve some of their own intellectual complexity and energy.

Even professors who do not feel equipped to draw conclusions about the interplay of disability and their subjects can raise questions. Here are just a few examples, although this volume contains many more: In criminal law, you might ask what accounts for the overrepresentation of people with disabilities within the criminal justice system. You might also ask to what extent the insanity defense, in its different iterations, reflects historical understandings of disability. In torts, you might ask how ableism shapes our collective understanding of a “reasonable person,” or you might allow room for debate about whether mentally ill defendants can be responsible for intentional

3 California Rule of Professional Conduct 1.16(a)(3).

torts. In civil procedure, you might ask how ableism impedes access to courts generally, or note the barriers that civil rights plaintiffs, including those with disabilities, face in attempting to certify a class. In property, you might ask how a history of institutionalization has affected disabled property ownership. The list goes on. In any subject, you can take the opportunity to highlight legal scholarship by diverse voices, including those with disabilities, or you can note the presence of legal actors with disabilities. After all, a disability lens raises questions that are broadly applicable—about how the state responds to the needs of vulnerable populations, what equity means, and how to create a society broad enough to accommodate a wide range of bodies. It asks us to look at actors within the legal system as real people with real and complex bodies, moving through real spaces. Any thoughtful engagement with disability is so much more than nothing, which, sadly, is what many of us experience.

But I don't think that changing our analysis of the substance of the law is adequate. A true disability lens also demands that we examine the built and cultural environment of law school. I saw disability, and felt it, in a legal academic culture that I experienced as relentless. In a culture of endless stamina and productivity and norms of self-presentation. In the embodied struggle that shaped and limited my intellectual endeavors.

My first semester, textbooks broke my walker on Week Three. My second semester, I spent forty hours taking exams and got sick in the middle. The day after those were over I embarked on an (ultimately unsuccessful) sixteen-day law review write-on competition before beginning a job the next day. The day after the job ended, I returned to school. So it was for three years and counting. And I felt, and still feel, caught between my desire to do law in a way that is physically sustainable, my core belief that legal spaces should expand to creatively hold people with a wide range of bodies and minds, and my understanding that it is not about me at all, but the clients whose interests I have been taught I must prize above my own.

I have spent a lot of time thinking about how we might make law school a better place for disabled students, and, in so doing, begin to shift the norms of the profession for the benefit of all involved. In the many conversations I have had with disabled law students, I am struck by the fundamental modesty of our requests. We understand that we are entering a profession that asks for all that we can give, and we are prepared to offer that. Although there is certainly transformative potential in looking at the world through a disabled lens, many of us would gratefully accept the ability to move through the world safely, and with a modicum of dignity.

I once took an (admittedly unscientific) survey of a group of disabled friends. I asked them what would be the one thing they would change in their classes if they could. They said, "Get rid of attendance policies." To be clear, their concern was not that disabled people would be penalized for occasionally missing class. Their concern was that such a policy incentivized able-bodied classmates to go to class when sick, meaning that immunocompromised people never felt safe in class.

We have attended meetings about snow removal, broken elevators, and curb cuts. At a summer internship, I argued politely with people who should know better about unlocking a bathroom door because I could not manage a key. (I was not successful and spent several months going to a different floor to relieve myself, to the detriment of my morale and work product.) A friend once calculated the amount of time spent on the phone requesting a minor accommodation and came up with the equivalent of several days. Fixable problems all. Even the most successful disabled students feel some amount of grief in wondering how their trajectories might have been different had they not expended such significant energy on the very basics of access.

I don't deny that even these basic problems require resources and labor. But when I think about the depth and breadth of the problems that drew me to law school, problems of systemic injustice and poverty, I occasionally sigh impatiently and think: *Maybe we could just fix the damn elevator.* And in the longer term, maybe law schools could embrace more complex stories about who is worthy of help and reflect on the fairness of expecting disabled students to endlessly power through institutionally imposed barriers.

And yet the weirdness of it all is that being a lawyer remains the honor of my life. I would endure the struggle ten times over for the chance to help even one person. I feel a kinship with the law precisely because it is messy like me. And because how you tell the story matters, I want to tell you that I had a group of friends and mentors, both disabled and able-bodied, who saw me in all of my self-consciousness and struggle and held me in ways that sustain me to this day. My desire to live up to a hard-charging ideal did not keep me from being much more open about all that bothered me than was customary in the rigid space in which I found myself. One thing about disability is that, for better or worse, it makes it harder to hide. I tend to wear stress on and in my body, which certainly makes it hard to navigate both spaces and relationships gently. But my core people, disabled and not, are living proof that with no special technical skill and little lived experience you can approach disability with mutual respect and fundamental kindness that is game-changing (hopefully for all involved). They help me believe in the possibility of a profession, and a way of thinking about law, that is openhearted, curious, and kind. And one that holds complexity with a kind of reverence.

II. Manifestations: On Being a Disabled Advocate

As I entered my final year of law school, something weighed heavily on my conscience—I had not served a single client. I had taken civil rights classes, written civil rights papers, and conducted civil rights research. But when the time came to do direct services, I demurred. I was terrified. I would like to think that I was terrified not of the prospective clients, but of what I could do, or not do, in my capacity as their advocate. To live in a disabled body is to live in a fundamentally unpredictable body. I have a significant stutter and my disfluency ranges from negligible to decidedly not. I worried that my hypothetical clients would need me to be fully present for them and my body

would let both of us down. This is not even to mention the plethora of access disasters that could keep me from them on any given day. While I believed, and still believe, that disabled lawyers have the right to practice in any field of law, I did not want vulnerable, marginalized clients to bear the brunt of my variation in their own highest-stakes moments.

I shared this conundrum with a law school classmate of mine, and he suggested that I apply to the Education, Defense and Justice for Youth program offered through the East Bay Community Law Center, a clinic affiliated with Berkeley that represents court-involved young people in school discipline and special education proceedings. Like the juvenile justice system broadly, the clients were largely students of color who, by the time they came to the clinic had a long history of educational struggle and poverty-related hardship.

When I applied, I shared more than was customary about my own story. I wrote that I had attended a disability-specific preschool in the Bronx that was socioeconomically and racially diverse. And that when the time came for me to start kindergarten, my parents moved my able-bodied twin sister and me to a more homogeneous school in suburbia so that we could attend the same school. I wrote that I appreciated that decision as I prepared to get my law degree but that it also meant that educational privilege was built into my journey. I told them, too, that I was terrified that my disability would keep me from fulfilling my responsibility to my clients, and that I hoped to use the clinic as a forum to face that fear. I was accepted.

The clinic itself was situated in a large cabin-like structure with colorful murals, a tree-lined backyard, tables for plotting boldness, and a buzzing client reception area. Here, the storytelling gets complicated, because I can't tell you with any level of specificity what I worked on. I can't introduce you to the young people I worked with and for in any level of detail. I believe that their (disabled) stories are every iota as worthy of your attention as mine. But as their former advocate, I must keep their confidences. I can say that as clinical students we were encouraged to look at the complexity of our clients' stories and move beyond binaries of guilt or innocence, ability or disability. Just as importantly, we were expected to face the real ways that racism, ableism, and poverty shaped our interactions with our clients, as well as the outcomes of their cases. We did so crowded around a small, round table each Thursday, sharing the intimacy that came with shared knowledge of information that could not be taken outside. We called clients by their names, and did the best we could to hold their stories.

When I look back on it, I believe that clinic was the most "accessible" experience that I had in law school. It was not because the built environment was flawless. It was not because I had every conceivable accommodation, although it was helpful to have a team of mentors and teammates who were intellectually and personally committed to my participation. Instead, it was precisely the recognition that people, behavior, and bodies are complicated that relieved me of the burden of operating entirely within able-bodied frameworks.

This recognition became apparent to me in the way that the team welcomed my disability into the space and worked collaboratively with me to help me navigate my work and the court system. I used my phone to text with clients when speaking was too much and navigated awkward introductory conversations with clients, their families, and judges. I teamed up with others for fatigue management. I was more open than I had been before about my anxiety. I wrote out everything I wanted to say before meetings, sometimes using pencil marks to note appropriate places to breathe. One of the three supervising attorneys drove me the forty-five minutes to court or to the juvenile detention center in the same building multiple times a week. There was uncertainty about my disability among some of the people with whom we interacted but less so than I feared. And, importantly, I felt widespread recognition that embracing my disabled experience was consistent with, and essential to, the work of clinic.

My ability to successfully navigate clinic also had much to do with the nature of the work itself, which was to ask nuanced questions about the way that disability shaped the behavior that had led our young clients to become court-involved. This was in part because special education law provides protection for behavior that is a “manifestation of disability” that it does not provide for more “standard” misbehavior,⁴ though the difference between those two categories is often a matter of storytelling. The stakes for that distinction are immense in the lives a young person. A determination that wrongdoing was a manifestation of disability, loaded though that pronouncement was, generally stopped an expulsion from moving forward.

Though I was careful not to substitute my own experiences for my clients’, I was struck by the familiarity of the questions I faced in clinic: How does disability shape our sense of who is worthy of resources? How does disability shape futures? Mine? Theirs? Who gets the privilege of being seen as complicated? Although we were so different, I hope that the visceral, embodied relationship I have with these questions made me a more compassionate and effective advocate than I would otherwise have been and allowed me to see them my clients more fully. More than anything, I hope that the young people who entrusted me with the intricacies of their lives will someday have the opportunity, the stability, and the resources that I have had to reflect on their own stories and find within those stories hope and recognition.

III. Search Results

I have so much compassion for the college student Googling her dreams. I wonder what it will take to create different search results. I imagine a disabled college senior undertaking the same wistful Google search I undertook, but coming up with a much broader set of stories. Perhaps she would find the disabled lawyers whom I have come to know. Those navigate the profession

4 20 U.S.C. § 1415 (2006) (a provision of the Individuals with Disabilities Education Act imposing an obligation to assess whether behavior for which a student receiving special education services has been referred for expulsion is a manifestation of disability).

with creativity, fortitude, and honesty. These messy, multifaceted, disabled stories propel me forward, and make me a stronger advocate. They offer disabled inspiration in its truest form. Now that I have made it to and through law school, I would like to make those stories available to all who search for them.