Conferencing, Canes, and Other Adventures

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Recommended Citation
Available at: https://digitalcommons.wayne.edu/woodwardreview/vol2/iss2/15

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Amtrak offers a ten percent discount if you have a disability. I had settled on the idea of this discount by the time I read about the attached requirement to “provide written documentation of your disability at the ticket counter and when boarding the train.” My written documentation is a blurry dark photocopy of a neurologist’s diagnosis, and I didn’t have enough time to see my current doctor for more documentation. The Amtrak website says that “acceptable documentation” also includes accessible parking tags. Making a photocopy would require parking somewhere that wasn’t a handicapped spot, and so the entire blue tag was stuffed into my briefcase along with notebooks and copies of what I was presenting. It worked better anyway, I reasoned, because they would be less likely to think it’s fake if it’s the whole tag and not just a copy. I was accepted onto two panels—one creative, one scholarly. No one ended up asking me for any

1 I discovered this in March 2020, as I was coming up on the four-year anniversary of my fibromyalgia diagnosis (March 2016).

2 People are already skeptical enough of my young appearance combined with the presence of a cane. They want to know—demand to know, sometimes—what “happened,” and the answer that they’re looking for is more along the lines of “twisted my ankle while out jogging” than “trauma and fibromyalgia.”

3 My General Practitioner had filled out paperwork before, paperwork that was passed along to my graduate program, but no amount of paperwork seemed sufficient as more and more were demanded, goalposts moving like some kind of nightmare where a hall is endless and every time the EXIT door seems near, it’s some kind of sick and twisted illusion.

4 Parking spots and parking tags are the only context that I can think of where I still use any version of “handicap” rather than “disabled” or “accessible.”

5 Think, here, about the windshield notes people leave for drivers with disabled tags who don’t fit the profile that the note-writers have in their head. Or folks who think disability is a choice, or result of poor choice—not enough yoga, that kind of thing.

6 Amtrak allows as proof of disability a “membership card from a disability organization.” My creative presentation for the conference is an essay called “Accommodation,” a satirical how-to that, among other things, pokes fun at the idea that disabled people carry a “Cripple Card,” which a person might think you carry when that person thinks that the ADA is an organization with a staff that can be called about matters such as restaurant seating issues.
documentation on the train, and so the several days’ worth of worry that I might be kicked off of the train somewhere in northern Rhode Island or southern Massachusetts were ill-spent hours of anxiety, though I thought little about this on the train itself. As I wrote some short fiction in my notebook about a woman in a pandemic, I hoped and wished that no one would end up sitting next to me. It was a mostly empty car early in the morning, the whole train jittery on the old tracks. The seat next to me was space for my cane and my briefcase, and it meant a greater likelihood that the mysterious illness we were starting to hear about would not be in my immediate vicinity for an entire train ride.

I was grateful for the solitude of Boston in the early days of the pandemic. When I tried to head up the stairs from the train station, I tripped to the point of having to put my hand on the dirty concrete that I had been (trying) to walk on. It was only as I started writing these last few sentences in the first draft of this essay that it occurred to me what might have happened in a pre-pandemic world, one where people would have likely been bustling all over even so early in the day. From a young age, from as young an age as I could possibly remember, my cheeks would burn red when tripping up and down stairs. Shame was ingrained in me early, and so from the age of five I learned it was safer not to

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7 I was presenting both panels on March 7th, 2020. Covid 19 was still being downplayed, as was mask-wearing. Mostly, the advice seemed to come down to “wash hands, use sanitizer.” By this point, hand sanitizer was sold out of stores, and it was being listed for exploitative prices on Amazon.

8 The hand that was, at that particular moment, without a cane

9 My imagination, something at the nexus of experience and anxiety: people would have looked at me like I should be an invalid, not attempting to be a person around them; someone might have tried to help without asking, touching my body or my cane as though they had the consent to do so; perhaps I would have been injured more, if I went unnoticed and was stepped on or pushed further down the stairs. There are so many iterations of this that I could, quite frankly, spend an entire essay speculating the possibilities alone.
make myself big or loud; such a lesson is how my great-grandmother’s watch caught on the netting of a fellow middle-schooler’s backpack one day, splitting the antique into pieces because I could not force words out to stop what I was witnessing in the moment. And so I found myself glad to be spilt onto those dirty city steps all by my lonesome; the shame was lesser in the moment, though my cheeks still burned from instinct.

It did not stop there: I walked out onto mostly empty Boston streets, the stuff of Left 4 Dead 2 and its ilk of zombie apocalypse games, though blood had not been programmed to stain the world around me, of course. I have never been gifted with directions; even though I grew up in Queens, navigating the very easily numbered streets of Manhattan still remains an impossibility for me, a mystery that I can’t crack no matter how many times it’s explained, rationalized, or reasoned with. This inherent foible, piled on top of cognitive symptoms—confusion, memory issues—made finding the hotel where the convention was being held a near unreachable goal. I imagined this was an easy task for most of my colleagues, a brief dedication of mental energy, but I became dizzy, tripping along the way, turning ways that were right and wrong, trying to pretend to the rare passerby that I knew exactly where I was going and every move that I made was actually intentional. The closer I got to my destination, the more groups of people I saw, the more pressure there was not to embarrass myself in front of witnesses. Eventually I managed to stumble inside of the right hotel.
In the course of trying to get up to registration, I made a fun\textsuperscript{10} discovery: escalators had become an issue for me. It didn’t occur to me that I hadn’t used escalators\textsuperscript{11} in the nearly five years since I started showing symptoms of fibromyalgia. It did not occur to me that I would have to lift my cane to keep it from wobbling with the motion of whatever jaggedly-rotating conveyor belt spun beneath the surface, or that the lights on the escalator steps would set off my light sensitivity; it feels like it should have occurred to me that the motion itself would make me dizzy, since so very much of movement writ large does. I wonder if the movement tricked my body into thinking that the motion signaled dizziness before it actually did. Despite all of this, I reached the appropriate level, I registered, and I picked up my tote full of conference paraphernalia. I made a trip to the restroom to try and fix my windblown hair\textsuperscript{12} at some point before or after\textsuperscript{13} registration. I went out of my way to find the panels I was on in the huge paperback book with all of the conference’s scheduling, and then sought those rooms out\textsuperscript{14} so that I wouldn’t get too dizzy, lost, or flustered later on.

\textsuperscript{10} It feels like the footnote on this use of “fun” is likely self-evident. Finish the sentence and I trust that you’ll figure it out.

\textsuperscript{11} In the interest of full disclosure, I tried using the elevators first, but they were confusing and I got lost in different wings on different levels. Given my track record of getting stuck in elevators—including once on my birthday—and my decades of nightmares about falling, I thought that escalators were the wiser bet.

\textsuperscript{12} There was nothing to do for my windburned cheeks except hope that they eased up before the presentations.

\textsuperscript{13} Even while taking notes during the conference about what happened when, events get mixed up. Memories can be a jumble that way, and fibromyalgia especially likes to scramble them.

\textsuperscript{14} And here we have the pre-existing condition to the pre-existing condition actually doing some good: anxiety would have made me look for the rooms either way, but now it works in service of the cognitive manifestations of my disability.
During this pursuit, I even saw a fellow scholar with a cane who was not, by the surface-detail assumed looks of things, much older than I was.\textsuperscript{15} There was a strange comfort in seeing someone like me, a sense of belonging, a hope (however realistic or unrealistic) that someone else perhaps understands the kinds of things I experienced just to get to this point. The moment was not undercut, exactly—perhaps it would be more accurate to say “layered with humor”—as a man looked between me\textsuperscript{16} and another woman with a cane, both of us coming from the same direction. He did a cartoonish kind of double-take, the sort of thing that you’d expect out of Daffy Duck, and I didn’t have to ask him to take a good guess at the questions and connections that he was trying to make: \textit{Are these women with canes together? If they aren’t, how can such a coincidence exist, two such women coming from the same place who don’t even know each other’s names?}\textsuperscript{17}

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My first panel was a creative one. There was a podium, but it was off to the side in this shadowy little corner. The panel chair, a colleague from my graduate school, set a chair in the middle of the “staging area” and informed me that I’d be reading first. I asked if I should take a seat in the chair for the reading, and after her nod as confirmation, that’s what I do\textsuperscript{18}. I read a sarcastic short essay about disability called “Accommodation.” It’s a facetious how-to, which involves the pearls of wisdom \textit{“Don’t be young\textsuperscript{19},” \textit{“Make sure that}}

\begin{footnotes}
\item[15] Some comments on my disability have been the enthusiastic insistence at, say, the grocery store that I’m “not old” (ergo, the implication goes, I should not need a cane).
\item[16] A woman with a cane
\item[17] The likelihood is that this is not the \textit{exact} wording in his head, of course. However, it was the sentiment conveyed by his gestures, by his demeanor. To be fair, I could hardly believe we were both there myself, and I’m one of the aforementioned women with a cane.
\item[18] I am, it turns out, the only one who reads her creative work this way, which makes me feel strange odd-duck-out feelings that I can’t quite articulate. Note: As one of the most stereotypical Virgos out there, feelings aren’t exactly my forte anyway.
\item[19] Refer to footnote 15
\end{footnotes}
“your disability is super obvious”20 and “Don’t forget your cripple card.”21 After I read, and after the other three panelists read, we all sat together for a Q-and-A.

I thought I was prepared. I’d just had an anthology pitch picked up about how marginalized identities intersect with how fiction is written.22 I’d had a craft essay about characterization and verisimilitude and disability picked up a few months earlier. I had just started a position as one of the Diversity & Inclusion Editors with the Journal of Creative Writing Studies. While I tended to focus my research on queerness and bisexuality, I thought that I was very prepared for this Q-and-A, to discuss disability and literature and all their complicated little intersections.

It did not take long for me to feel completely unmoored.

The questions started straightforwardly enough, so much so that I don’t remember them exactly, but they were questions of memory, humor, form, that kind of mostly technical craft-based thing. There were basic assumptions that audience members made, even seeing the cane as evidence of my illness/disability. Their questions assumed my mental illness, as well as a vague learning disability24 that I didn’t have.

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20 This “rule” is based around an alleged Good Samaritan, a visit to the post office, and my cane almost being stolen from next to me as I tried to pay for postage because “Certainly this isn’t yours!”

21 I genuinely did not know there was a requirement like this from actual companies like Amtrak before attending this conference. It boils down to a funny kind of coincidence, for a given definition of funny, I suppose.

22 Musing the Margins: Essays on Craft, Human/Kind Press, 2020

23 “Authenticating Detail and Disability Narratives,” So to Speak, 2019

24 This is tricky. While fibromyalgia can impair my learning, especially with the cognitive mess of fatigue and fibro fog and memory issues and confusion and all of that, the questions seemed to assume that I also had conditions akin to ADHD, which I never claimed and tried to correct as politely as possible so as not to claim identities or experiences that weren’t mine.
But then the questions became much more difficult, veering in the direction of who gets to write a story. One person even asked about who gets to be “a voice for the voiceless.” And, it being the early days of March 2020, *American Dirt* inevitably came up, though somehow I hadn’t expected it; I suppose it didn’t occur to me in terms of my specific essay, since my essay’s focus is disability and not Latinx and/or immigrant experience. “Who gets to write what stories?” seemed to echo in the room again and again, in various iterations. The conversation even turned to fact vs. emotion.

I was overwhelmed. Others on the panel had written about a relationship with a friend, a fellow teacher harming a student of theirs, and issues revolving around pregnancy and miscarriage. None of these essays felt like they approached questions of marginalized identity quite as directly as my own did. I love discussing issues of diversity and inclusion and marginalization and equity; this was not an issue. But I felt uncomfortable trying to field questions about what was “wrong” with *American Dirt*. It felt as though I were meant to be a representative of The Marginalized™, and as such give permission for

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25 While posed as a question, it had big “more of a comment” energy. I got the sense that they wanted me to say that it was okay to write X story from a perspective that was not their own.

26 This sort of assumption, perhaps obviously, undermines exactly what I was doing with “Accommodation.” I have a voice; I used my voice, and more directly I used my voice to highlight the way that people who assume my voicelessness are outlandish. This idea comes from a place of paternalistic savior-hood, the idea that unfortunate marginalized folks are not capable of telling their own stories, that someone abled, for instance, needs to come in to tell the disabled person’s story, or else how will anyone know?

27 Published January 21, 2020

28 I am neither Latina nor an immigrant, and thus cannot speak to the myriad experiences of people in these groups.


30 Most of the assumptions of this conversation felt uncomfortable to me, like the idea of “fact” in the essay, which is the realm of personal truth and particular experiences of the world.

31 I decided to cite the problems with it that I’d heard from Latinx writers online—especially the stereotypes and the commodification of such experiences. But, I was careful to reiterate that it’s better to listen to the people who are affected by a particular representation.
people to write the stories that they wanted to about disabled folks, etc.  

My argument—letting the marginalized speak for themselves, always acknowledging your position in a narrative—never seemed to quite suffice for this audience.

It felt like the questions were an academic exercise, something theoretical and hypothetical, the kind of conversation that one might call “invigorating.” But how could I explain that they would never fully understand the lived experience of moving through the world with a cane until/unless they did so themselves? How could I explain that people measure a person’s appearance against cultural narratives, that my age and my womanhood invited challenges to parts of myself that fellow grocery store patrons have no business challenging? How could I explain that you can experience invisible pain and have people doubt your illness and make participation in your own life more inaccessible than it should ever have to be? How could I explain the caution that ethically representing marginalized peoples of many varied intersectional identities required moving beyond thinking of such people as “voiceless” or, perhaps as incapable?

How could I explain any of this—aside from the essay which I had just read to them?

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Even without my laptop inside of it, carrying around a briefcase full of paper and notebooks and a blue handicap parking tag caused overwhelming pain. My body cannot handle too much at once, and what might qualify as simply a slightly busy day for someone

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The “etc.” here stands in for literally millions of people whose life experiences I couldn’t speak to; I couldn’t even speak to everybody’s experience with fibromyalgia, not with both accuracy and specificity. So, really, the “etc.” is doing a lot of work here.
else (a train ride and presenting at a panel) proved Herculean for me. To make matters worse, I was late taking my afternoon dose of fibromyalgia medication—the stuff that keeps me from even worser pain and brain fog and related unpleasantness. Even though I thought I was running late, I had to stop to take my medication, just another inconvenience on the ongoing list of frustrations that I have with my body, but don’t actually keep track of.

Once the doors opened to my next panel’s room, I randomly sat next to the man in the middle of our panel table. I didn’t know anyone in the room until a professor from my alma mater appeared in the audience, much to my surprise. The professor came up to us and said hello, and then informed me and the man sitting next to me that we actually shared an alma mater. All three panelists were presenting on genre fiction in the creative writing classroom, and we all seemed to be of like mind that genre fiction should be included. The panelist from my alma mater and I even used the same quote from Thrill Me: Essays on Fiction by Benjamin Percy.

I was out of breath when I presented my paper, my body showing its wear from the day’s over-activity. I stood at a podium this time. And as I struggled to read my

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33 You might wonder why I’d bother with all of this hassle if it makes my chronic conditions act up, if it literally hurts to do this. I liken it to one of the reasons that it’s important for me to be in front of a classroom teaching: I want to establish disabled presence, to take up the space that we are told in ways overt and insidious that we do not belong in—with words, with legislation, with structures physical and otherwise.

34 Spoiler alert: I actually wasn’t.

35 In a generous reading, this is an active choice to keep myself from becoming bitter. In a reading that is perhaps more realistic, I don’t have the brain energy to dedicate to holding on to that kind of information.

36 This had happened to me on the first day of classes for the semester, too. I had scheduled a flu shot across campus and raced back to the building where I had to teach. A student stopped me as I was reading through syllabus policies to draw attention to my breathlessness. I thought about this while presenting my paper, how unpleasant it had made me feel. I had no choice to continue reading my paper, cooperative lungs or no.
paper, I felt the weight of the sacrifice that I needed to make in ways that so many other conference attendees do not, what it means for me to do these expected professional things in a physical space like a conference where I could potentially network or find publication opportunities, where I could increase my chances of finding a place in academia.

I learned at some point during the panel—before the panel started, I think, or maybe it was during the Q-and-A session—that the man presenting with me was partially deaf. That strange comradery returned, a deeper and more realized version of what I experienced with the woman I passed by who also had a cane. The comfort of not being the only one in the room, of not being the only person who can speak to inclusion and access, of not being the only person who wants to speak to inclusion and access\textsuperscript{37}, was invaluable. Even with the physical difficulties actually presenting my paper, everything about the atmosphere relaxed me. The questions from our audience focused on asking for reading recommendations and suggestions for pedagogical structuring in the classroom. It felt like, despite what had led up to that panel throughout the day, academia could be carved into the kind of place where people like me were more than a mere inconvenient footnote\textsuperscript{38}, rarely thought of except for\textsuperscript{39} accommodation\textsuperscript{40}.

Maybe academia could be carved into the kind of place where people like me had a seat, cane and all.

\textsuperscript{37} Especially in a nuanced and experientially informed way
\textsuperscript{38} Where we could be our own voice rather than letting some other voice call us the voiceless
\textsuperscript{39} The legal minimum
\textsuperscript{40} And sometimes not even that