

The Politics of Disability Performativity

An Autoethnography

Devva Kasnitz

Disability is a concept that grows as we think about it, forcing us to adjust our conversations in vocabulary and rhetoric depending on which disability world we inhabit or address. Understanding disability starts with exposure to disabled people's bodyminds in their own spacetime and an appreciation of disability expertise. The disability justice movement pulls the intersectional performance of disability out of the intimate sphere so that it can play a role in policy, an analytic where anthropology should shine. This article is particularly addressed to anthropologists with a new interest in disability and critical disability studies scholars with a frustration with anthropology. I use exemplary analysis of actual dialogues drawn from an autoethnographic record of my own perceived mobility and speech impairments to explore my biopolitical positioning as disabled. Anthropologists have the capacity to move disability theory forward, feeding it with ethnographic fuel. While the anthropology of disability uses insightful ethnographic methods to understand specific impairments in specific contexts, the reflexive turn in anthropology has not yet embraced disability. We are still better off remaining individual disability experts; our collective efforts are still an "embarrassment to power." This article, as part of a collective special issue, aims to change that.

Disability is an ingenious way to live. (Neil Marcus)

Coffee Cups

At the diner my husband likes because the locals come in wearing overalls and talking cows, the waitress comes with her coffee pot and starts to serve us in the old-fashioned cups and saucers from which I slurp as they are much too top heavy and flat for me to pick up. She says, "I'll just pour you a half a cup, so you don't need to worry about spilling it. I'll come round and keep refilling it." I respond, "*Oh, thank you, can you make it the top half?*" (From my autoethnographic field notes, October 2015)

Disability is one of those concepts that grows as you think about it, forcing you to consider related concepts: identity, impairment, illness, health, intersectionality, and more. Were it not complex, the emergent field of disability studies could not be sustained. As an academic and political exercise, disability studies reframes disability to bring out the nuance appropriate to different projects.¹ We adjust our conversations in vocabulary and rhetoric depending on which disability world we address.

1. Here I use "nuance" as others might use "critical." I postulate that at this time, all new good anthropology or disability studies is "critical" in its subjectivity. Pure description is an impossibility. We expose our biases in both what we say and do not say. Sins of omission of discussions of relationality and power constitute serious faults. See Meekosha and Shuttleworth (2009) and Hartblay (2020) for more on critical disability ethnography, a product that, like all of disability studies, centers the expertise of the disabled and exposes the relationality of the writer.

Disability Justice Is Good to Think

Understanding disability starts with exposure to disabled people's bodyminds in their own spacetime and an appreciation of disability expertise. The disability justice movement pulls the intersectional performance of disability out of the intimate sphere so that it can play a role in policy,² an analytic where anthropology should shine. Disability by definition is remarkable. Disabled people live with the reality that the public wants to define that remarkableness and the knowledge that if they do not manage their human relationships carefully, their remarkableness will be used to control them. This was noted as "the Management of Spoiled Identity" as early as 1963 in Goffman's 1963 sometimes forgotten classic and rephrased by Rosemarie Garland-Thomson (2009) writing about how disabled people recognize, at least intuitively, that it is their role to set non-disabled others at their ease. There is significant pushback to this from the exasperation of disabled people tired of that effort, to people who consciously refuse to do it—or who do it in their own and unexpected ways. Someone like artist/writer/performer Neil Marcus, who has the same diagnosis of dystonia that I have, always does it with kindness and humor.³ I have more anger, but we meet in our recognition of the risks

2. We are all indebted to our colleagues of color for articulating "disability justice"; see Mingus (2017).

3. Idiopathic familial generalized torsion dystonia. See http://www.disabilityhistory.org/people_marcus.html.

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and the power of in-your-face disability performativity (Marcus, Kasnitz, and Block 2016).

A Journey into Autoethnography

This article is particularly addressed to anthropologists with a new interest in disability and disability studies scholars with a frustration with anthropology. Its goal is to further conversation by using exemplary analysis of actual dialogues drawn from an autoethnographic record of my own perceived mobility and speech impairments.⁴ I use both phenomenology and systems theory as analytic grist to this data to explain my biopolitical positioning as disabled.

As a student in the 1970s I was hesitant to study disability and to write what came to be called autoethnography. It remains professionally dicey. Many current anthropology faculty still have trouble seeing a disabled student doing anything but autoethnography.⁵

Why autoethnography (Block 2020; Forber-Pratt 2015)? To bring out nuance. I moved from Australia to Sicily over 3 years of studying reproduction and immigration for my dissertation, but my best data on the Sicilians' conception of female physiology came from kitchen table and bathroom conversations about whether or not it was a good idea for me to have a baby. Sumi Colligan (2001) also reports this experience of our disabled bodies being the conversational foil to understanding general ethno-embodiment.

How autoethnography? As in "Coffee Cups," because of my speech impairment, I use chat, text, and email as others use the telephone and face-to-face conversation. I have verbatim transcripts of all my classes and most meetings I attend from employing Computer Aided Real-time Transcription or CART as an accommodation. As data, I mine these texts altered only to protect others' anonymity. I make no claim to generalization. Today I am content to demonstrate how anthropological tools make my life more meaningful to me with verbatim electronically captured data.

Anthropology's Contributions to Disability Studies

Anthropologists have had a significant impact on the development of critical disability studies, as is evident in various reviews and curricular interventions.⁶ In the twenty-first cen-

tury, some anthropology graduate students are embracing disability studies from the beginning of their careers, while seasoned anthropologists have turned to this subject as an active part of their later personal and professional lives.⁷ However, too often institutionalized anthropology eschewing a perceived "service" thread in disability studies misreads the field's theoretical and methodological contributions as "only applied." Anthropology is also wary of autoethnography and its place in cultural studies (Forber-Pratt 2015), as if participant observation was ever successful without intense and even risky, if unexpressed, self-reflection, a hallmark of the early disability and anthropology engagement tradition I follow here (Frank 2000; Murphy 2001).

Interrogating the shared category and experience of disability is, I argue, what separates disability studies from simply the study of disability. It distinguishes disability anthropology or anthropological disability studies from simply the "anthropology of disability" (Shuttleworth and Meekosha 2013) and it welcomes autoethnography. Disability anthropologists excel at describing others' points of view in context. We make theoretical contributions to disability studies about demedicalizing and decolonizing disability, highlighting indigenous meanings.⁸

Despite a growing disability anthropology, most anthropologists of disability are only now discovering disability studies. Anthropology's institutions have failed to embrace disability studies despite the feminizing, browning, queering, and now the crippling of anthropologists. Perhaps this is because for some, these developments, like applied anthropology, suggest a loss of status for the discipline. How can we think about the decolonizing of disability given the historical resistance to the topic in our discipline? Yet there has been at least one anthropologist on the board of directors of the Society for Disability Studies (SDS) for 27 of its 35 years, serving as president for 28% of that time. Disability studies has welcomed ethnography in all of its permutations, yet anthropology's bureaucracy has remained profoundly ableist, even when three disability ethnographers sat together on the executive board of the American Anthropological Association (AAA).

7. Here I thank Lucy Cohen, Alice Kehoe, and Jay Sokolovsky for their gift of conversation.

8. Most reviews look at publications; I will simply list names of anthropologists not in this collection who have been active not only in early disability scholarship but also in institutional organizing. A partial list would include Irving Zola, Joan Ablon, Louise Duvall, Gerald Gold, Joseph Kaufert, Russell Shuttleworth, Carol Goldin, Jessica Sheer, Nora Groce, Robert Murphy, Sumi Colligan, Karen Nakamura, Gaylene Becker, Linda Mitteness, Gelya Frank, Cheryl Mwaria, Lois Keck, Mathew Kohrman, Zev Kaliphon, Elaine Gerber, Olga Solomon, Susan Gabel, Pamela Cushing, Gail Landsman, Miki Iris, etc. The Society for Disability Studies started under Irving Zola's mentoring in the early 1980s with three fresh anthropology PhDs—Groce, Sheer, and Kasnitz—on the founding board. Despite 35 years of the Society for Medical Anthropology's (SMA) Disability Research Interest Groups, which never failed to organize AAA meeting sessions, "disability" as a keyword in the AAA meeting program guide is new.

4. See a description of this in Kasnitz and Block (2012).

5. I believe some unresolvable discomfort with the disabled or racial other sparks inappropriate anger because people hate feeling embarrassed. See Ralph (2020). In American disability worlds, a polite "No, thank you" to proffered help is often met with indignant anger: "Well, be that way about it!" People need to be needed. However, when others decide what you need, when you need it, and how you need it, it becomes oppression.

6. There are many reviews of disability anthropology. See Kasnitz and Shuttleworth (1999, 2001), Battles (2011), and Rapp and Ginsburg (2013) to start.

Anthropology's four-field division has not helped. We talk to each other less and less. Medical and educational anthropology both study disability but rarely talk because the disproportionate size of the Society for Medical Anthropology within the AAA not only renders it hegemonic but also makes it difficult to DE-medicalize and hence destigmatize disability. Linguistic anthropologists have embraced the study of signed languages, nonstandard speech, and autistic communication (Ochs et al. 2004). The subfield of bioarchaeology has also recently engaged disability's long-standing significance for the species (Byrnes and Muller 2017). The growth of interest in disability within anthropology holds important potential, but without knowledge of disability studies, many confound disability, illness, debility, impairment, and chronic illness. Some medical anthropologists of chronic illness are careful NOT to claim disability expertise because they are aware of this critique. In this work, it is also essential that we tease out ageism and ableism both separately and in interaction, but not collapse them. My deliberate personal strategy to further institutional disability anthropology has been to seek out these colleagues, present with them at meetings, encourage joint publication, and create email list conversation threads.⁹

Anthropologists have the capacity to move disability theory forward, feeding it with ethnographic fuel. While the anthropology of disability uses insightful ethnographic methods to understand specific impairments in specific contexts, often from a western or indigenous medical diagnostic perspective, this approach often fails to deploy a dynamic relational concept of disability. A perusal of recent presentations at AAA meetings shows that family and care provider voices are privileged, sometimes in the service of "studying up." However well done, this risks silencing disabled subjects, particularly people who are nonverbal or speech impaired and who have nonstandard voices to which the ethnographer must literally learn to listen.¹⁰

Words Matter beyond the Word Police

My ideas depend on a largely temporal distinction between impairment and disability, although not in a classic biology/society dualism.¹¹ Both are socially constructed. Here I do differ from others, including in this issue, who collapse or interchange impairment and disability because their community does. In disability studies we debate, or passionately refuse to debate, binary word choices such as the long-standing argument between "disabled person" and "person with a disability," or "people" versus "identity-first" language. Students learning about disability studies want to be told which is correct. I eschew

the "word police" in favor of conversations about meaning. To avoid offense, we can talk about disability without using either "disabled people" or "people with disability." If the focus is connecting to a social movement, writing this article, or teaching, I use words that I hope will best communicate my ideas. None of my choices are for variety, "honoring," or not offending. I understand I am a "person first." I have embodied anomalies that are socially marked as "impairments" because of "discrediting attributes" as perceived by others, not as lived by me.¹² Once perceived, impairment is a route to disenfranchisement; I am "disabled" by that perception and disenfranchisement. Impairment may not trigger an experience of disability oppression; but when it does, I become a "disabled person" precisely because my personhood is disabled by attitudes toward my perceived "impairments."

I also eschew all of the overused wordplay such as dis/ability, dis/ableism, able-disabled, and challenged, even if it is not gratuitous. I do not use "disability" in its noun form comfortably except as a name for a perceived demographic category (Friedner 2020) and as a name for an experience. I particularly avoid "disabilities." Concretizing disability as something plural or with a range of severity seems so divisive that I will restructure a sentence entirely to avoid it. I would rather destabilize the disability/not disability binary than explode disability into the plural. I acknowledge that my socially perceived "impairments" are multiple, as are the barriers I face and the contextually appropriate accommodations I expect, but disability is a unifying experience.

Bigger Is Not Better

I find marginal utility in definitions of disability that inflate it to the largest minority or in reminders that anyone can join our ranks at any time. I do, however, join Lakshmi Fjord, Lenore Manderson (2009), and Sunaura Taylor (2017) in a broader view of the value of disability theory to understand the production of disabled social and environmental ecologies and disasters, be it family or forest. An expanded notion of "disability" can provide a better understanding of "affordances" as opportunities (Gibson 1966) and "accommodation" as enabling. For example, one way to reframe the need for radical inclusion in professional organization meetings would be to mark accommodation needs as relational and interactive. Everyone should fill in the "Accommodation Request" box with notes such as "I don't sign. I'll need an interpreter for any presentations by deaf participants," or "I'll need a revoicer for Devva at these times when I hope to meet with her."

I think of this strategy—which I call "community-based accommodation"—as exemplary of Danilyn Rutherford's (2018) idea of how nondisabled people who are family or allies have "disability proximity." Significant disability proximity is a part

9. See archives of AAA meetings.

10. See Hartblay (2020) for a discussion of how as an ethnographer, she slipped into an altered sense of time to interview someone with extremely slow language production.

11. See early British social model theorists such as Michael Oliver, whom we just lost (Malhotra 2019).

12. Thanks to Goffman (see Shuttleworth and Kasnitz 2004) and the still-useful stigma model.

of what I describe as a larger societal “disability exposure” that allows a “cross-impairment synergy,” a recognition that we share a unique and heightened energy across specific impairment labels that we cannot access separately, to emerge from a disability justice perspective and to hold powerful group advocacy potential.

Apprehension of Disability

In American culture, disability—like race, gender, nationality, and any other imagined identity characteristics—are situated in a world where it shifts from background to foreground in our quotidian lives. This is not without risk. Certain experiences cause perceived impairment to pop into the foreground as problematic, the “light bulb” moment when an impairment becomes a disability, a spacetime out of spacetime experience. This starts from or can lead to embarrassment and then to the apprehension of disability status. When repeated often enough in multiple contexts, embarrassment as a tool of ableism wanes and a consciousness of ableism and of disability identity emerges as a strategy to manage the categorization of disability as a social vulnerability or risk.¹³ Chronic illness, temporary injury, and all kinds of bodymind anomalies in contextual spacetime can trigger the apprehension of disability status. It takes repetition and some reflection to create the disability identity “access intimacy, interdependence, and disability justice” that disability advocates express (see Mingus 2017).

When people have significant exposure to disability, they can become adept at recognizing disability expertise and helping in a way that makes disability background and other activity foreground. Applying the concept of “affordance” (Dokumaci 2017), which I think of as openings in social structures that create opportunity or well-being, I may choose to gracefully accept help I neither need nor want, but I am clear that it is not my affordance but my helper’s. This experience is what I want to share in my micro-autoethnography here where “microaffordances” are but tiny cracks. That is why I started with my “Coffee Cups” vignette above. I allowed the waitress’s need to feel kind lead me to truthful humor.

Blank Faces

I tell my students:

I just met someone in the hall who introduced himself and told me what our connection is, that he teaches the intro disability studies course and attends SDS. I said, “*Oh, nice to meet you.*” I started to actually talk to him, that blank face. “*Oh, okay. Okay, let’s try again.*” I thought. I tried again very slowly. Blank—where others would say “Again?”—he gives me only a frightened rabbit expression with no clue to let me

know where he lost me—and this person knows me from disability studies! That makes the situation a little sticky. I thought, “*He was clearly embarrassed.*” I thought about embarrassment, and I realized that I don’t have the luxury of being embarrassed.

If I get embarrassed, I can’t get my needs met. I can’t do anything. It is completely immobilizing. Embarrassment is just not on my agenda. Having the luxury of being embarrassed is ableism. I know that the best care providers just naturally dispel embarrassment. It doesn’t accomplish anything and is an e/motion that puts you out of motion. (Class CART transcript, 2/28/2018)

In the next vignette, like “Coffee Cups,” I again show how disability pops into my own consciousness and intrudes on my life while I am otherwise engaged because of a social interaction. Remember, my impairment reality is obvious although uncommon, but my chosen accommodation is not. I can drink/slurp the top half from most cups without picking them up or even touching them. The bottom half I can only splash over the room should I try to pick it up and I tend to burn my tongue with straws in hot coffee. The other common solution to the “Devva” problem waitresses assume they/I have is to offer a disposable cup so they/I need not be concerned about breakage. I can’t even touch such a cup without knocking it over because it is too lightweight.

Alone?

This foregrounding of disability caused by the actions of clueless others has little relevance to my activities except to block them (Shuttleworth 2002). Perhaps my marching gait is a bit off, but my endurance is not.

I “#Me Too” marched in snowy and poor Cincinnati—my first time in the city. I had a blast except for the woman who came up to me and blocked my path when I jumped up on the sidewalk to quickly get a better view of the crowd to guesstimate the size. She said, “Are you alone?” Of course, I instantly knew I’d been hit with crap, again. Was she embarrassed for me that I seemed alone? Did she think I needed better care? Was I too “ugly” to be out alone?¹⁴ Here is where I resent my speech impairment. Here are the snappy answers to her silly question that I would have liked to say: “*Oh yes, (grabbing her arm) I’m all alone—will you help me? Will you buy me lunch?*” “*They just let me out of the hospital/jail.*” “*No, but my friends can go without my supervision for a short while if you need help.*”

I muttered something about gross paternalism and infantilization that she neither heard nor would have understood as my friend said, “NO, she’s with us.” After I ran to get back in place, I marched backwards and stared at her.

13. See Ralph (2020) for more on how violently acquired disability experience medicalizes vulnerability and risk in exchange for services and “care.”

14. See Susan Schweik (2009), *The Ugly Laws*, for a discussion of disability in public.

Then I did a few pirouettes and started to skip. (Class CART transcript, May 16, 2018)

Embarrassment and Disability Apprehension

I am indebted to Hughes and Paterson (1997) for their classic phenomenological elevator spacetime disability conundrum vignette. They describe how when the elevator doors open, and someone gets on and asks Hughes a question that does not have a yes/no answer, he can at best stick the footplate of his chair in the door to give his CP (cerebral palsy) mouth time to answer. I know this “innocent” questioner well.¹⁵ S/he is usually embarrassed that they have made a disabled person go through the effort to answer; they may break into profuse apology, asking more rapid-fire questions we do not have time to answer. Or they may be disturbed that their time is now engaged past the usual elevator spacetime. Although tiresome, we “crips” are accustomed to this. Some of us get the setting-people-at-their-ease, however much we wish for the reverse courtesy. When spacetime permits, I do the setting-at-ease by assuring people “*I know I’m hard to understand, this is NOT news to me.*” If I want any kind of relationship with the embarrassed, I must help them over it. The need for others to join me in employing communication accommodative microaffordances, such as turning a face toward me or putting down a phone, is often central to such conversations. With a recognition of cross-impairment synergy, this is true whether we “present” with “expressive” impairments, strange voices, mechanical voices, proxy voices, confused voices, signed voices, slow voices, and/or with “receptive” impairments, sound processing, hearing, listening, contextualizing, or combinations.

There is, however, a darker side to embarrassment and disability when someone is embarrassed for someone else. While I have realized I do not have the luxury of feeling embarrassment, to assume I am embarrassed, or that anyone is or should be embarrassed for me is profoundly ableist. I may need help with many things, but being embarrassed by my experience of disability is not one of them. Embarrassment over the mere existence of disability is oppressive. In these cases, my interlocutors feel free to ignore public norms of word and deed to invade physical and psychic space to “assist” me in my self-presentation to minimize the disability stigmata their own unbridled perception of disability has bestowed on me. They are both the author of the problem and seek to be its solution. They can and will, without asking, either seek to “fix” me or to control me so “my” disability is minimized according to others’ views. This loss of self, this “management” of personality, is ableist intrusion. In the case of people who used to be called “retarded,” this phenomenon is magnified. While I endured that R-word epithet only from spitball-throwing boys on the

school bus, others were and still are not that lucky. They experience an extreme ableism for which I still use “handicap.” Someone encounters “handicap,” as I use it, when oppression goes beyond a disabling of personhood to remove it altogether. Philosopher Eva Kittay (2001) addresses this circumstance when she writes of the joy she takes in her daughter Sessa’s affective expressions. At the same time, she acknowledges Sessa’s profound care needs; although Sessa is nonverbal, Kittay highlights a reciprocity others do not see.

Although I experience both mobility and speech impairments, sometimes people are aware of both and sometimes not. My experience of disability oppression is, however, singular when it is foregrounded in my vignettes. Sometimes my mobility issues surface in an unusual gait; other times it is my inability to write in small blanks or carry certain things. For example, at the bank when I limp in, I am offered a desk and a chair; this is very nice except I can only handwrite standing up or kneeling on the floor. Then, after I start to speak, I am offered a pen and paper. Sometimes I wave my crip fingers at them. Sometimes I answer no to “Can you write that down?” Sometimes I say okay and kneel on the floor, as I do at home. Perceptive tellers learn to think twice before asking a limper and mushy-speaker crip to write. These autoethnographic vignettes reveal the subtle variations in how speech impairment becomes speech disability, and how mobility impairment becomes mobility disability in mainstream life. Like others, I continually invent microaffordances and direct accommodations. There is a reason I accentuate my odd gait and hold my ticket in my “bad” hand when boarding a plane: I want the preboarding affordance.

On the Accommodation Octopus

The concept of accommodation currently enshrined in American regulation is a problem. It both over-individualizes and overgeneralizes. Ignoring community accommodation, it places the burden on the individual to give up some affordances in order to get others, while it generalizes building codes as if all wheelchairs were the same height. It is about others demanding that you change to be disabled their way. For example, in academia, a student’s most common accommodation is extra time. What is the most valuable thing we have in life? Time. What is the last thing most employers want to offer as an accommodation? Time.¹⁶

The health care system has become a gatekeeper to accommodation. This exacerbates its place as an inappropriate economic engine, creating an accommodation industry. Starting in childhood, medicine is entangled in the provision of basic education. In order to get or get out of “special education” services, you have to invoke the power of medicine. I remember asking my pediatrician to get me out of gym and get me into advanced placement French instead. My mom wrote the letters

15. Thinking about these apprehensions of disability is a continuation of a conversation between me, Pam Block, Neil Marcus, Russell Shuttleworth, Mathew Wangeman, and Susan Fitzmaurice.

16. For a glimpse of the backlash, see <https://www.forbes.com/sites/richardvedder/2018/06/26/disability-accommodation-on-campus-some-unintended-consequences/#ba4bc2a1fc1d>.

he signed. Later, at 30, when I decided to try learning to drive, I needed a letter again. I asked my neurologist for a letter saying I could drive. He asked, "Can you drive?" I said, "*I don't know; I need a learner's permit!*"

In this multitentacled system, in the conceptualization of the problem in the moment, in the way in which you look for help, or advocate for change, if you are in the realm of disability or the domain of illness, you do it differently. People move through these domains in life; you cannot act on all of them all at the same time. That is why I am so careful to describe "my" disability as an experience of a certain kind of exclusion, as opposed to describing it as dystonia, which is the diagnosis, or as speech and mobility impairment, which is the realm of functional limitations. I seek accommodation because of disability; the specifics are because of how impairment as a social category manifests in different contexts.

Week One Introductions in an Online Class

How do I greet an online class? How do I make them allies? I use humor and performance to introduce disability in person. I want to perform disability online in a way that I cannot avoid doing in a face-to-face class. I want to disrupt students' notions of disability and impairment. I start by posting a video of myself spinning wool surrounded by a living room strewn with dozens of skeins of prize-winning yarn I have spun. I show them something that they cannot do and that no one expects me to be able to do. I look for that "pop," a kind of culture shock as a way of introducing myself. I started talking during the filming.¹⁷ About halfway through I realized I was unintelligible and started speaking nonsense, real English words, but nonsense. The prankster in me wondered, would they notice? Then I posted this introduction.

Well, my arms ache from clicking Blackboard buttons. The software is really not designed for a crip like me with too many repetitive movements of my constantly moving spaz hands. Can't type in wrist braces at all. The base of my thumb is swollen, the heel of my mouse hand calloused.

Online teaching is both a boon and a disaster for crip faculty. No ramps to find, print as large as you want it, no minute to minute deadlines. But more typing than anyone should do, trends toward more dependence on voice recognition is not universally accessible, not all schools help with "alternate" formats or video captioning. But this is so much fun. Who wouldn't want to teach for peanuts in your jammies and without your impairments on display? (Blackboard class post, 2/3/2014)

Online teaching is counterintuitively more intimate than a face-to-face class. Even the "quietest" student speaks. Participation is transparent. Disability experience disclosure is the norm, as is student mutual support. I ask them, "*What's*

missing from the video?" They answer, "Captions," but at the same time say that they were beginning to understand me by the end. "*You mean the gibberish?*" I ask.

Week One Introductions to a Face-to-Face Class

Scheduled to teach undergraduates at a school new to me, I get an automated email message from the student accommodation office, my first, that a student's prior accommodation request is "canceled." I respond:

You say: "*Student Disability Services have been canceled for the following student.*" Sounds like she was deemed ineligible. If so, I have two conflicting reactions. First, it's none of my business. No faculty should know that you found a student ineligible because it brands them as a whiner or a liar. Second, if you said no, I would want to speak to her myself to be sure she knows that I may be willing, even if you are not. However, I bet she told you that she didn't need your help in MY class. The reason why this is canceled is all me, not you or her. First, I don't give tests. Second, I give all my students alternate formats to choose from, disabled or not. I anticipate need.

"Canceled" is a strange choice. The underlying trope is "*Our previous notice that you are required by law to supply this accommodation is now canceled.*" How about: "*We are happy to inform you that the following student has indicated that s/he will not need the listed accommodation in your class. Thank you for providing an accessible learning environment and we hope that you have not yet expended extra energy fulfilling this particular request.*" (Email correspondence, 2/1/2018)

If I, as disabled faculty, found this communication rude, how must others feel? This is not how I want disability represented. I received a reply.

We review our messaging templates at regularly scheduled intervals and your recommendations will be taken into consideration at this time. (Email correspondence, 2/2/2018)

At this school, as is common, disabled student accommodations are met by one office and disabled staff needs by another. Luckily, these two offices DO talk to each other in this case. While as a new disabled faculty member I was not clued in about the faculty office ahead of time, and was sent to the wrong building twice, for one hard of hearing (HoH)/deaf student's request, I was told, it MUST be negotiated weeks ahead in a phone call, despite the fact that phone calls are inaccessible to me as any HoH/deaf student would surely understand. The business of student accommodation provoked faculty disability. This possibility was outside their disability world imaginary, causing my experience of disability to pop again into that foreground of embarrassment and vulnerability, and I seethed.

For the first class, I had a captioner trying to revoice; that was my idea, a bad one. She felt embarrassed and exposed, standing beside me instead of sitting in a corner behind her machine

17. See <https://www.youtube.com/watch?v=c887SWOJR2c> ("dr devva spinning and talking").

preprogrammed to type “inaudible” with a single stroke. From the back of the room, students with advanced knowledge of the field feed her the vocabulary. It helps but also confuses as disembodied voices come at her. This captioner is not a good revoicer, but others might be. The Chinese students flee, some during and some after the class. They may be seniors, but this is a test of their English skills they do not dare take.

The second class has captioning, CART projected for all to see. Most captioning in class is “closed,” available only to eligible students via Wi-Fi to their laptop. My request that it be “open,” that is, projected, hit a glitch. It seems the software does not allow a font size large enough to be seen from the back of the room.

The accommodation office also takes the initiative to call in a pair of ASL (American Sign Language) interpreters who get Deaf Culture. Doesn’t take them more than a few moments to see they are in Crip Culture land with me. It takes them most of the first class to get the protocols and hand signals for HOW they are supposed to revoice. Recognizing kindred souls, I stop them when they begin to paraphrase instead of revoice. Looking deep within their eyes, hands on cheeks, in performance mode for the students, “Your voice is mine, word for word. You don’t need to understand. Listen, repeat, forget; listen, repeat, forget; listen, repeat, forget; listen, repeat. That’s your job. (In fact, if they relax about trying to understand, they will.) Your mouth is MINE,” punctuated with a kiss. Everyone cheers. Lesson one in “Embodiment and Disability” is delivered.

I tell the students to take note of how meaning emerges from, or is muddled by, the sheer physical and joint mental effort our communication accommodations absorb, and to be aware of the role they play individually as solution or barrier. Not paying attention goes beyond being a bad student; it is ableist. I do not expect them to work as hard as we four: two interpreters, a captioner, and me, all of us at least 20 years older than they. But meet us halfway.

My Listener’s Brain

I give the students a piece of disability apprehension theater I have developed over the years. Just as I performed my ASL interpreter turned revoicer’s brain above, I perform my naive listener’s brain mindstream when it first encounters my live speech. I tell the students that I know they are thinking:

Oh, my goodness, look at her talking. Look at how her face CONTORTS. Who could ever understand her? She just keeps talking. Oh no, she is looking at me. What will I do if she asks me a question? How will I even know it’s a question? What should I do? Do the others understand her? Am I alone? (Class CART transcript, 2/9/2018)

Good humor and intellectual surprises work to dispel embarrassment. The class is still awake at 9:15 p.m. The Hoff student only learning ASL is happy as she lip-reads the revoicing interpreter and then checks the captioning. One interpreter

must stop putting her hand over her mouth when she is embarrassed if she does not understand me. Maybe later the two of them, both big women, will figure out how to join the circle rather than sit in the middle of it. The students with sound processing problems are happy with the captioning. Everyone likes the idea of getting the transcript. Later it will dawn on them that because attendance is required, a student may miss class but make it up by reading the transcript and posting comments to the class website, a task much harder than just showing up.

It is a constant dance to both manage all these classroom affordances and accommodations AND to teach. I tell myself that the mere routine exposure to so much proximate disability expertise to apprehend IS the lesson. I explain my cross-impairment synergy process to the class.

I have a thought and I look over there at you and that changes my thought a little. Then I look at the revoicer, and I say half the thought, and then she gets it wrong. That changes my thought. Then I say it again. And because this is all so slow, there is lots of time to think. Then one ASL interpreter feeds the other in ASL the words she missed in English. At times the HoH student feeds it in ASL to the interpreter because her disability studies vocabulary is better than the interpreter’s. Meanwhile the captioner may get what the revoicer misses, but for me to know that, I must turn around with my back to the class to see the screen. (Class CART transcript, 2/7/2018)

I try to curb students’ thumbed conversations with people not in the room. It breaks the one-person-talking-at-a-time rule. After all perform their brain, students respond well when told,

“I know how hard I am to understand. My bargain with you is that if you still your inner voice (and put down your phone) to give your brain more space to listen, I promise to be funny, to dance and mime, to keep you awake, and to say things that are memorable.”¹⁸ (Class CART transcript, 2/7/2018)

Zooming to GoToMeeting

Technology is blessing and curse as it intersects my accommodations. We meet in real time via a combination of voice and chat. I feel pressured to type into chat fast and not fix typos, and the chat is not all mine. Other people interrupt me even when I am giving a formal report. My current solution is to prepare ahead such a good written report that I anticipate any questions and to also develop a close enough working relationship with the correct committee chairs that they are prepped to answer if there are questions. A good meeting is one where I do not need to talk. If I do, I fear the uncorrected chat will be judged and I will be found inarticulate—my audience will apprehend a “disability” I do not have! How

18. I love the contradictions between my speech impairment and verbal art. See Bauman (1975).

do I manage my need for patience with the predominant culture that may even privilege some hyperactivity (Nishida 2016)?

Independent Living Removal?

I am in a play, a farce, it seems. I have Skyped into an important most-of-the-day meeting. Because of my speech, we always have chat open so I can type. We have two-way video and speakerphones at both ends. We start with a brief formal meeting; the chair solicitously asks for my vote and I unmute and remute for them to give my “Aye.” Then we have a guest, and the camera for my visual is just a few inches from our presenter’s butt. They improve my sightlines and we all laugh. After our speaker leaves, it is time for the six of us to get to work. My virtual self appears to be about 10 feet from everyone else. I have a great view of backs. (Later I learn no one thought to move the table closer to the outlet.) My chat messages go unseen. I interrupt the conversation via speakerphone and try to say, “*Please read the chat.*” The leader gets up, walks over to me and reads—no, actually paraphrases—my typed words in the third person, as if I were not there, for the others. She only sees the most recent of my typing as it scrolls off the screen. With her nose inches from the camera, she stands bent over my laptop self. She asks me to be quiet while SHE types TO ME. I type:

[12:57:50 PM] Devva KASNITZ: *can you put the chat close to yhou*

[12:58:13 PM] Devva KASNITZ: *I can hear huou. Why r u typing to me?* (Skype chat transcript, April 2016)

Now, I HATE to send such bad typing out, but my customized typing software does not link with chat, and there is no time to correct a chat the intended audience seems loathe to read. This would be funny if the organization involved was not a 30+ year old disability service and advocacy one. Should I be surprised?

Aaron the Revoicer

People who use a revoicer often develop an oratorical style. We hear our own words repeated—a unique feedback loop. They may, like me, put the punchline at the end of the sentence so that people do not try to speculate what they think I am going to say. Speculation takes over from listening to what I do say. Truly listening is rare among our culture of multitaskers. Perhaps Moses broke the first set of tablets in frustration not so much over the Golden Calf but that they did not LISTEN to him. Perhaps Aaron’s shame was not allowing the Golden Calf but failing to revoice Moses’s words to the multitudes firmly enough?

What makes a good formal revoicer? Like Aaron, someone who is not too shy, who speaks up. Someone who, if invested in the topic, is not insecure about their own ideas, and does not need to be the one leading the discussion all the time—

they need to focus on what the speaker is saying and HOW they are saying it rather than on what they would say or how they would say it. A good short-term memory helps. One protocol with strangers’ revoicing is: listen, repeat, forget; listen, repeat, forget; whereas people who know you well use that knowledge. A good revoicer is also someone who looks directly at the speaker with an expressive face so that the moment they lose the speaker, the speaker knows it. Understanding is interactive and must trump any embarrassment felt when it is wrong and must be corrected.

Families have been the center of communication access for both early- and late-onset speech impairment. Families have had to conceptualize meaning and express it to the outside world. Only recently have speech therapy, signed language interpreting, and alternative and augmentative communication become recognized sciences or activities. As these fields professionalize and services are reimbursable as medical costs, there is lucrative territory to defend with significant processual and emotional clashes among scientific, familial, service sector, and disabled people over validity and process.¹⁹ Within the family, these needs figure into the micropolitics of care. In many cases communication “care” never goes beyond the family. Where it does, we see the development of social and professional accommodative strategies very different from the family. My first-choice accommodation is revoicing. Institutionalized by the work of Segalman (2009) in national telecommunications law, it is a little known but required “speech to speech” relay service for all speech-impaired people where their words are repeated (revoiced) to their listener by a trained third-party “communication assistant.” This is now gaining national recognition using my term as “revoicing” in remote and, more often, face-to-face communication.

As people with speech impairments develop clearer ideas of using revoicing as a tool, their perception of what constitutes best practices may be very different with family, friends, or strangers in that role. Because communication is so fundamental, it can form the basis of alternative families that develop in disability contexts (Friedner 2020). Part of this difference has to do with who owns the problem. In India or in Africa, anthropologists are asking whether it makes sense to talk about the disabled family (see Addlakha 2020; Friedner 2020; Whyte 2020). Clearly, there are differences between revoicing as a family strategy where intimate knowledge of the speaker is primary; social revoicing where friends are usually the gatekeepers to participation, and relationships must be carefully managed to avoid misunderstanding and fatigue; and professional settings where accuracy is critical but there may be no prior interpersonal relationship. In the last case, the revoicer probably has been trained as an ASL interpreter or captioner. S/he might be a generic personal assistance-provider

19. Alternative and augmentative communication strategies are both individual and concretized in some sectors. Hot debates over techniques such as facilitated communication and rapid prompting method are current and beyond the scope of this paper.

with idiosyncratic experience of clients who need revoicing or help with alternative and augmentative communication devices, along with other mobility apparatus.²⁰

Small Talk Communicative Personality

As an anthropologist and as someone with a changing speech impairment, the data collection process for my ongoing auto-ethnography has revealed some of my own strategies. I had to give up small talk a long time ago. Like so many stigmatized people, I do best when I am funny; I put on a show and use physical humor. Embarrassment, again, can lead to a breakdown in communication. My disability imaginary is a communicative world free of disruptive embarrassment and its consequences: anger, confusion, guilt, and withdrawal. I want to avoid loneliness and promote its opposite (Kulick and Rydström 2015). I want my relationships unconstrained by disability in general or by preconceived notions of a disability hierarchy in addition to real differences due to specific impairment. Anecdotally, I can say that all my friends with generalized and even painful movement disorders that also affect their speech report that their speech impairment is their most troubling disability experience. Along with Alison Kafer (2013), we work toward an accessible future as one where familial, social, and professional revoicing blend and all support participation.

What Do Allies Get?

Allies understand that disability is not about health and that disabled people can be the healthiest in the room, living and dying well. They assume competence and seek comprehension. They offer appropriate assistance based on proximity and exposure to disability that values our disability expertise. They see the complexity and the dynamics among and between impairments and cross-impairment synergy. They understand the project of grasping disability process in all bodyminds and spacetimes with meaningful insight into our variation as well as the ever-changing environment. Our academic allies “get” the sophistication of disability studies. Those in anthropology understand that the time is up for an anthropology of disability innocent of critical disability studies. Allies grasp that disability is big business in America with a huge neocolonial structure of competing NGOs tied to certain activities, occupations, and particular impairment categories. They do not believe that folks with intellectual impairments should have any less choice than others. They understand the catch-22 that the whole service sector, while useful, is also draining cash that could put people in homes of their own with assistance in the next bedroom down the hall or with tools to start their own company. They see that access to intimacy is something that people

who experience different kinds of impairment might want as they form relationships with each other based on and contributing to cross-impairment synergy.

Concluding with Microaffordances into Future Imaginaries

Disabled people care about place. When we enter a room, we scan it. *If I’m in that corner and then I can do this, but I can’t do that, that chair is too low, but if I get this chair, it will be too high.* This is work that goes on just to figure out what is around you, how it may or may not limit you or extend you, and how much you can manipulate it. We may do this consciously or tacitly. My micro-ethnographic role is my ability to witness and explain this process. Creative accommodation demands it. Call it a reframing of disability pride. It is something missing in much disability-related design. Disabled people rarely commission design. Designers design what they want to design for a purpose they want to meet. Disabled people are the colonized consumers. Too often, it is assumed that there are not enough of us for economic viability of design products without medical reimbursement. This makes the reimbursement source the true customer to please. The voice recognition software once developed for people who could not type used to be trainable to nonstandard voices. As it has gone mainstream, that feature is gone.²¹ Features in Microsoft Office 2010 offered flexible possibilities, while the 2016 version introduced a barrier to its use as it became more standardized.

We occupy disability (Block et al. 2016). We beg the service sector to see us as we want to be seen. We use the metaphor of “decolonizing disability” carefully. I have been called an infrastructure activist within anthropology and disability studies as I perform disability for different purposes. Within the American Anthropological Association, we have reached a crossroad. We understand the dominant discourse in disability studies, the Americans with Disabilities Act, and “reasonable accommodation,” but as a discipline we are missing a deeper understanding and have not yet operationalized our knowledge to make a more accessible profession.²² We cloak disability exposure and expertise in “individual confidentiality.” Members who call out errors do so at considerable personal risk. The reflexive turn in anthropology has not yet embraced disability. We are still better off remaining individual disability experts; our collective efforts are still an “embarrassment to power.” This article, as part of a collective special issue, aims to change that.

21. Google’s Project Euphonia is currently seeking to expand impaired speech recognition: “Google likely to unveil ‘Project Euphonia’ at I/O 19 to give the speech-impaired ‘their voice back’.” Kyle Bradshaw, April 26, 2019, 1:47 p.m. PT @SkylledDev. <https://9to5google.com/2019/04/26/google-project-euphonia-io-19-speech-impaired/>.

22. The American Anthropological Association has hired an access coordinator as of June 2019. There is hope.

20. Speech impairment is quite common among people with generalized movement disorders such as CP, dystonia, and stroke.

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