

## CHAPTER TEN



## *The (Dis)Ability Double Life*

*Exploring Legitimacy, Illegitimacy, and the Terrible  
Dichotomy of (Dis)Ability in Higher Education*

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### *Introduction*

OUR EVERYDAY INTERACTIONS ARE SHAPED BY MANY FACTORS, THE most significant of which originate within us. The intersections of our identities, personalities, and past experiences form a lens that affects how we see and experience the world and how we think about ourselves and others. Our thoughts about our intra-cultural and intercultural experiences shape our feelings, which form the most basic bonds of our relationships with one another and with ourselves. These thoughts are also what form our relationships with our culture(s). Though these two ideas of communication, cultural and personal, currently exist as separate, but perhaps related disciplines, they are intrinsically connected by our experiences. Our relationships with culture and with one another inform how we react to, cope with, and internalize our thoughts and experiences.

What follows is an exploration of what I call the terrible dichotomy, the idea of being legitimate and illegitimate all at once, and the conflict that stems from it. This dichotomy occurs when parts of our identities are validated and other parts are oppressed. This stems from the intersectionality that exists when multiple parts of our identity are at play at once, for example our culture and our gender. My il/legitimacy centers around the ideas of ability/disability and my social roles as student/faculty, but they can exist in any parts of our identity, including for example age, spirituality, nationality, gender, race or socioeconomic status.

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A good friend of mine is Native American, but looks Caucasian. He doesn't like celebrating Thanksgiving and takes offense when he hears Native American words used out of context. People are often offended by his objection to holidays and words that have become second nature in American culture. This is his intersection of cultural and personal relationships. When someone calls him Chief, he takes offense to it, just as I take offense when someone uses the word "retarded" to describe a redundant or frustrating situation. The rejection of our offense (despite the difference in situational context) is often the same.

"Don't get so worked up! It's just a word."

In this chapter, I explore the idea of the terrible dichotomy and intersectionality in interpersonal and intercultural contexts. First, I will look at the oppressed or illegitimate part of my identity as a student with a disability. Next, I will look at how the terrible dichotomy exists within the legitimacy of my identity as a faculty member. Finally, I will discuss how the culture of disbelief influences how people with disabilities are mistreated both culturally and personally. The conflict described in the following pages affects both my relationships with others and how I relate to the culture of my people, those with non-visible disabilities or disabilities not marked on the body. My learning disabilities (dyslexia and dyscalculia) are typically seen as childhood conditions that can be easily overcome. The cultural thoughts about this create conflict for me as an adult student and as a professional faculty member.

### *Student*

"You seem upset, what happened?" Ruby asks me over lunch. She is my best friend and knows when I am hiding something, especially something unpleasant.

"I'm having more problems with grad school. I can't explain how insulting they have been and how much I have come to resent the administration, especially my disability advisor."

"Tell me what happened ... all of it."

"It was all over the phone, I was expecting a call to resolve a debacle over a textbook. I ended up filing a complaint about my disability advisor." I take deep breaths between words, "I resent that I have no say in how they deal with my disability. I mean, the term *disability advisor* implies that I need to be advised about my own disability, which I have had all my life, by someone who is not disabled! My advisor, April, wouldn't give me access to a textbook I needed, and today her supervisor called me to follow up."

"What's the supervisor's name?"

"Sharon. She was already convinced that I was wrong. Here's what happened ..."

I relay the following conversation to Ruby with as much clarity as I can. "Dana ..." Sharon sounds upset saying my name. "I'm calling about the issue *you* recently had with April." She is playing up her role as legitimate since she is a supervisor and employed by the university. She is also reminding me of my illegitimacy as a student who, apparently doesn't know better than to talk back to staff members.

"Okay." The "issue" she is referring to is the fact that I need my textbook in a readable format that has not been provided for me. My class is progressing without me, and I am falling behind.

"April is doing her best to help you."

"Okay." I don't give a shit what April is *trying* to do. I just want my textbook.

I listen for an explanation or apology, which I know will not come. Silence. She's trying to make me feel guilty, but it's not working. I need April to do her job so I can do mine.

"You need to understand that what she is doing, she is doing because she wants to help you."

Now I'm really pissed off. All I hear is bad grammar and blame. So much wrong has been done to me in the name of help, and each time all these people accomplish is further marginalizing me by not letting me make my own decisions. It doesn't matter what her intentions are, I'm failing out of grad school because she cannot get me access to the course material. This is the definition of her job, and Sharon expects me to backpedal because she has good intentions.

"Okay, that's all well and good, but I need my book. She keeps pushing back the date when I can get it in a readable format. I've done everything asked of me. I purchased the book, submitted it weeks ago, and now the class has started, and I need the book. I'm already late on an assignment."

"Well she's doing her best."

At this point it becomes clear that Sharon is more concerned about her coworker than me. I want a transaction, Sharon wants a reckoning.

"April and I are trying to help you, but it is clear you don't want help." Ruby interrupts my story ...

"Help you? Didn't your undergraduate counselors try to help you, but advised you to take the wrong classes to deal with any accommodations you might need?"

"Yes, it nearly prevented me from graduating! If I had a nickel for every person who tried to 'help' me ..."

I feel my blood pressure spike, again. Retelling the story is like reliving the pain all over again. I see nothing and no one, I just feel rage. Ruby fades away, and what comes into focus is one clear, simple notion: oppression. The room gets darker, my blood gets hotter, and my vision narrows. The heat from my veins feels like they will boil the tears accumulating in my eyes.

"So what did you do? What did you tell Sharon?"

I snap back to the restaurant, to the present, to Ruby and her inquisitive look of concern. "I turned on my heel, slammed the mailroom door, and gave her a piece of my mind. —

"How dare you ..." I whispered in a low rage. "How dare you say that to me? Do you have any idea the hell I have gone through to get this degree?"

"I ..." She starts, but I cut her off.

"No! No, you don't!" I'm getting louder now. "You have no idea who I am, what I want, or how much I sacrificed to be here!" Now I'm yelling.

"Dana." She uses my name partially as a vocal filler, partially as a reprimand. Either way, I have never felt like someone doesn't deserve the privilege of my name, my identity coming out of their mouth, until now. "You are in violation of the student code of conduct."

Now the tears come like water discarded from car windshield wipers, fast and haphazardly. I try my best to choke them back but it is futile. I cry a lot more than I like. Tears seem to come every time I have to ask for something.

"Your whole department has violated the rules of the university and broken the law!"

"Dana, you are out of line. I can have you kicked out of school for this outburst." Her words are slow and steady. They are calculated. I hear a smile grow in her voice. Now when she says my name, it is no longer filler. Now she uses it to target her threats. The person with the most power in these conversations is the person who (seems) to have the most control. I have heard this threat before from others, mostly when they want to silence me or want me to go away.

"Well, you can try! Good luck with that."

"Wow." Ruby says, deliberately trying to sound underwhelmed. "That's some bullshit." Our normal friend protocol dictates that we both editorialize the situation. We talk about why we are right and the other person is wrong. We make each other feel supported and understood. We banter about the clever remarks we could throw back at our adversaries. But today, I'm too upset for that. Ruby lets me sit in silence for a while.

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This instance is reminiscent of so many other instances where I suddenly found myself fighting for my legitimacy, fighting against oppression misinterpreted and trivialized as a mere interpersonal conflict. Usually, these situations progress normally, without conflict of any kind, until I reveal that my needs as a person with disabilities are different from those who have the power to grant, or keep me from my least restrictive environments. This is every time I have asked a professor for an electronic copy of the syllabus, each time I need an extension or extra time on tests. The repetition is exhausting.

"Don't go into it with your mind pre-blown." This is both his advice for me and a reference to a sitcom we saw last night. He's trying to advise me on a very serious situation and lighten my mood at the same time.

I'm reminded of some other advice I received from the president of the Disabled Services Center. Never judge. She was referencing a student with a disability who accused her of not having any sensitivity for disabilities, since she herself had none. What that student didn't know was that she successfully advocated for her son's rights and accommodations through his entire primary and secondary education.

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It's 8:25 a.m. I grab my pastry from the catering table and take my seat, and suddenly my anxiety swells in my chest again. I have a sense that things aren't going to turn out well here, but I remind myself—don't judge, don't go into this with my mind made up (or pre-blown). A pre-blown mind can be a self-fulfilling prophecy. I shake my head to loosen the negative thoughts and let them escape from my brain, out my ears, and off my shoulders.

After the introductions and what I interpret to be some verbal ego stroking, the two proctors (a mentor and a protégée) do for one another, we begin. The mentor, Maggie, reminds us all to turn off our cell phones. She begins in on a tangent about technology.

"I don't allow my students to have cell phones or laptops in class. I just straight-up ask them to leave. What do you do?" she says to her colleague in the front row.

"I tell them they can't have any technology of any kind. Period."

"Really?" says another. "I just tell them it hurts my feelings."

"I can't be the police," says a professor from the back row. "It's their own demise if they have their technology out."

Now back to Mentor Maggie. "Oh yes, I try to keep a cap on it because I don't want anyone shopping on *Victoria's Secret* in class."

I am mortified. I can feel my face morphing into at least ten shades of red. My hands begin to shake, though I'm not sure what exactly is causing me to tremble. The rage? The embarrassment? The shame?

She turns and looks at me, "Oh yes," she says pointing at me, "*you* can have your laptop out." The entire group turns and looks at me.

I can't think about this. Don't cry. Don't cry. Don't cry. I repeat this mantra. Mentor Maggie becomes distracted in another conversation as she distributes the first of what I understand to be many handouts. I turn my attention to Protégé Polly.

"Do you have what you need?" she genuinely asks.

"Do you have this in an electronic format?" She is in the front of the room, and I am in the back, but the room is small enough for her to hear

me clearly. The problem is our conversation passes the ears of three other professors in my row.

"Uh, well ... I. Um ... let's see." I knew it. I *knew* she wouldn't have it. "No Dana. Sorry." I really do want to hide my disappointment, but I have no energy for that now. That energy was (and still is) spent on not crying.

"I don't understand why not. I sent you that e-mail specifically telling you that I use a screen reader, and I'd need these documents in an accessible format."

"I guess I didn't understand what that entails." She is young and apologetic. "I can e-mail this to you, will that work?"

"Well I need them now in order to follow along."

"Why don't we just put this up on the projector?!" One of the professors in my row has invited herself to the conversation. She is well meaning and wants to help, but this only multiplies my discomfort.

"She needs it on her laptop," Protégé Polly announces to the room.

The room breaks up into spontaneous discussion as she opens her computer to send me the e-mail. She has the presence of mind to ask if I'd like a PDF or a Word doc.

"Word, please," I say with only a shadow of sincerity in my voice.

Mentor Maggie comes over to see what the delay is. They whisper at the front of the room to one another and gesture to me in the back of the room. There are no words for my embarrassment.

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Mentor Maggie comes over to me and says, "If you were to get this in an e-mail, would that work?" She wants a simple *yes* or *no*. But there is no simple answer. The truth is, it depends on how much work she has done to make these documents accessible for screen readers. The room is still in discussion, and there are three other professors who are voyeurs in this conversation. I can't explain to her all the details of what makes a document accessible, but the presidential directive issued four years ago does. I decide for the sake of saving face to go for the simpler of the answers.

"Well, yes, if you e-mail me the handouts, I can pull them up on my laptop." But I never say that I can *read* them. Mentor Maggie leaves the room to send electronic versions of the handouts. On the way out, she mouths "*I'm sorry*," and pats me on the shoulder. I glance up to see the three other professors looking at me and stifle a shudder.

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I had to tell her to re-start the workshop. She wanted to wait for me to pull up the document and copy/paste it into my screen reader, and read the damn thing. No thanks. I've been enough of a spectacle for one morning.

Protégé Polly spends the next 35 minutes going over the handout she e-mailed to me. I spend the next 35 minutes contemplating the general fucked-up-ness of the situation and occasionally try to keep myself from imploding or bursting into tears.

She moves on to the next handout. I go to my e-mail to find the e-mails from Mentor Maggie, who is still not back in the room. I open the documents, and they are not accessible. I'm looking at a picture of text, and not actual text, rendering my screen reader useless. Now, my computer really is only a machine good for games of solitaire and status updates, all the evils that Mentor Maggie suggests.

"Alrighty, I'm going to break you up into pairs, with one group of three, since we have an odd number in the room." When she gets to me she indicates that I'm in the one group of three. "Maybe someone can read the handout to you?" she gently offers.

That's it! This is the statement in a series of statements serving as double-dog-dares to get me to storm out and slam the door.

My group mates, all tenured professors, smile empathetically at me. They are silently and calmly urging me to stick it out. I appreciate their kindness, but I cannot eat this pile of crap handed to me with the good silver flatware the proctors have laid out.

"Can I see you in the hall please?" I say to Protégé Polly with the same disdain I would reserve for a spoiled child.

I have spent my morning walking a tightrope, trying to strike a balance between what is right (self-advocacy) and what is expected (compliant silence).

"Was there a problem with the documents?"

"Yes. Yes, there is a big problem with the documents. I can't believe this! I tried to get this all worked out with you two before this workshop, so I could avoid this very situation. The documents are not accessible, and the thing is, there is a presidential directive from 2008 that requires all documents for all uses on this campus to be compatible with screen readers and accessible under the Americans with Disabilities Act. Not only are the documents not accessible, but you weren't prepared to deliver them to me. We could have worked this out days ago! But here's the thing: I could have dealt with all of this, it would all have been less than ideal, but manageable if you hadn't set me up for failure. Maggie not only stated, out loud, that laptops were strictly prohibited, but engaged the whole group in a conversation about how people with laptops in settings like this only use them to buy lingerie! Then the very next thing I have to do is pull out my laptop in front of the group! You made me look like a jackass to these people! I've been outed and set up, and that is inexcusable. I'd never do this to any faculty or any student, and for some reason, it's acceptable to treat me like this ..."

I halt myself. I could say more, but I realize I'm panting. I managed to get all these words out without taking a breath. Protégé Polly is staring at me, her mouth slack, her eyes wide and, if I'm not mistaken, misty.

"I'm so sorry," she whispers.

"No, I'm sorry." I draw a long sharp breath and wipe away my own tears that have streamed down my face. "I'm upset, it's true, but I should not take it out on you."

"Would you like to wait out here for Maggie?"

"No, there is nothing she can do. It will take days to get the documents accessible, and she can't unsay those words from the beginning of the workshop."

"Okay, is there anything I can do?" she says earnestly.

"No." I catch my breath. "I think it's best if I leave. I'm not leaving out of anger, or because I'm upset. I'm leaving because I really want to get the most out of this workshop, and I can't do that without proper access."

Polly nods, and we both head back inside. I collect my things without looking anyone in the eye, but I can feel them all on me despite the cacophony of the room. I shuffle down the hall and scurry to my office a few buildings away on campus, swallowing every sob that tries to surface itself. I have done nothing wrong, so why do I feel so shameful and embarrassed?

I make it to my office, shut the door, and dial my partner, Joe. When he answers, he doesn't say hello.

"They didn't understand, did they, honey?"

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The workshop proctors brought their own socially constructed ideas of non-visible disability to the workshop. They knew they would have to interact with someone who has a non-visible disability, yet they did not stop to check their own perceptions and compare their expectations with the reality of the situation. Even the other people in the room, the witnesses to this moment of oppression, reacted according to their misinformed views. A few of them watched in silence, for reasons I cannot know, but some of them spoke. Those who spoke only reacted on an interpersonal level. They wanted to make me feel better, or perhaps they wanted to make Maggie and Polly feel better. No one acknowledged the power discrepancies, inequities, prejudices, or insults that were present. No one even acknowledged that this could happen again or how many times it has happened before.

### *Culture of Disbelief*

Fraser (2007) describes a culture of disbelief, referring to the skepticism those without disabilities have towards those individuals with disabilities, specifically non-visible disabilities. There is something about not being able

to see the issue marked on the body of a person that makes others suspicious, particularly if you require exceptions from the normal standards (accommodations). What follows is a discussion of how this culture of suspicion affects interpersonal and intercultural communication.

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The sobs come hard and deep after Joe's all-knowing salutation.

"They outed me in front of the entire class!" I cough out.

"I'm sorry that happened to you, honey. You don't deserve this." His voice is steady and sure and masking a sense of outrage on my behalf.

"I'm just so tired of feeling like a child. Why am I crying?! I'm an adult, a bona fide grown-up. Why is it that I can't get anyone to treat me like that? I'm either an adult without a disability, or disabled and, therefore, a child." I skip over the details of the situation. He doesn't need them, and they are irrelevant at this point. Between his disability and mine, we've witnessed more kinds of mistreatment than I care to recall. We have both been labeled stupid by the very educators who should have recognized our disabilities. We were both told we are lazy. For a while, he was literally labeled as retarded while attending a private school. Despite the fact that he is a man and I am not, our disabilities are both non-visible and our experiences so similar, it is eerie. What's important now is how to recover and move on.

"You know you could have laughed out loud at them; you could have turned it back around."

I'm sobbing, and incapable of laughter. "I don't know if I could have done that."

"Sure you can. Dana, you are the future. You are the future students, the future faculty, and the future of education. Paper and pencil are already obsolete; soon they will be ghosts of classrooms past. These people are holding on to what little control they have left in the classroom." His words are a soothing balm to my soul, which feels like it has a nice case of road-rash.

"She actually said to the group that students in her class are probably shopping on *Victoria's Secret*. Like that's the only thing I could possibly think to use my computer for! Updating my status and shopping for lingerie." I choke out the words between sobs.

"Goofing off in classes has been around since, well ... the beginning of classes, long before computers. In high school, I used to put my comic books inside my history book, because I just didn't care about that class, but you're not one of those people. You really care about education, both your education and the education you give your students. I guess it's hard for them to understand anyone who wants to learn so bad that they jump through all the hoops that you have to with your disability."

"I can't believe they are holding on, so tightly, to this illusion of power and control."

"You're reality sitting right in front of them, right there in the classroom."  
"I can't believe the way they treated me! What have I done to them? I'm just me, and that's a terrible, terrible thing."

Then Joe repeats the analogy we use most often to comfort ourselves in these situations. "Would you take a wheelchair away from a handicapped person just because some able-bodied people might use it for a joyride?"

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The differences between those with visible disabilities, or disabilities marked on the body, and those of us with non-visible disabilities are salient, but we are allies. The context of oppression and accommodations that we deserve and that the law eventually acknowledged are considerably different. But the feeling of oppression is not. The falling away of your stomach, the rising blood pressure, and resulting tension in your veins is the same. The depression, anxiety, and paranoia that hang on the words of others stays with us and bonds all of us with disabilities. Just because my disability is not marked on the outside of my body (it is visible if you are looking at a brain scan) does not mean it is *invisible*. This is a term coined by people without disabilities, but with good intentions. There is never a moment in my life where my disabilities are invisible to me. Just because they may be hard for others to see does not make them invisible; at best this makes them camouflaged.

### *Terrible Dichotomy*

The battle of legitimacy/illegitimacy is at the center of much of the oppression the world has known (Freire, 1970/2003). The notion of legitimacy and illegitimacy creates a terrible dichotomy. I am both legitimate and illegitimate at the same time. I have rights as a student, but my disability sometimes negates those rights on some level. The same phenomena can be seen in the struggles I face as a faculty member. Though my role is different in both of these scenarios (student versus faculty), the struggles I face are consistent. The active and sometimes unintentional ignorance of the people in the academy regarding issues of ableism and inclusion creates conflict with my identity. The same can be said in many situations where a person's identity is threatened because of an inextricable part of their identity, including ethnicity, sexual identity, religion, or age. In other words, if someone challenges something that defines you, the result is conflict, specifically a struggle for legitimacy.

Freire (1970/2003) tells us that we are oppressors at the same time that we are oppressed. We suffer from and participate in our oppression. The same is true with the dichotomy of legitimacy. The terrible dichotomy is this struggle for recognition, acknowledgment, and acceptance. It is the act

of being legitimate and illegitimate all at once. Because of my insecurity of my legitimacy and validity, I often find myself unable to take back power when I really need to. Several interactions I discuss here reinforce a feeling that I am in some way wrong just for being myself. Sometimes having a disability can be seen as an inconvenience for others, because they have to bend the rules. Despite the laws, directives, and policies that guarantee my rights as a person with a disability, sometimes voices of disapproval and angst at my requests for accommodation (which in my mind is also disapproval and angst of my identity and my culture) ignite anxiety. I have seen these exchanges as threats to the justice of my identity. Threats are harmless; they are only threats unless, of course, they are *perceived* as credible.

Perception is reality. We are calm if we perceive our environments as being calm. If we perceive our environment as being hostile, threatening, or containing some degree of risk, then we are likely to be anxious and react. Normally this reaction requires just enough energy to neutralize the threat or to help us gain control of our immediate situations. These reactions vary given the contexts of our situations.

The terrible dichotomy can result in a variety of situations and perceptions. For me, it resulted in my determination to secure the acknowledgment and recognition for my identity as an individual who struggles every day with disability, and the other 650 million people worldwide who are members of the disability culture. The problem is that, at some point, we all face challenges to the legitimacy of our identities and cultures. The difference from one individual to another and from one culture to another is how we will rise to meet that challenge.

### Note

1. Normal is subjective, and problematic. The status quo is to specifically mark anything outside the norm as different, such as accommodations for disabilities. But society does this without consensus and arbitrarily.

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## SECTION IV



### *Creating Pathways to Authentic Selves*

**T**HE FOURTH, AND FINAL, SECTION OF THE BOOK INCLUDES THREE chapters that demonstrate how cultural-critical autoethnography requires constant self-reflexivity that provides different paths toward greater understanding of self, other, and society. Some of the chapters articulate pathways that are situated along historical, present, and future points of departure/arrival. Other chapters highlight how mass-mediated technologies via the Internet serve as salient avenues in the ongoing process of self-discovery. *Sensemaking, coordinated management of meaning, and cultural dialectics* will be introduced as organizing structures in terms of uniting autoethnography and communicative processes.

#### *Sensemaking*

Since the 1970s, sensemaking has represented a theoretical framework used by communication scholars interested in applying more humanistic ways of understanding human behavior in various contexts (Dervin & Naumer, 2009). Several theories of sensemaking exist, with a focus on intrapersonal, interpersonal, and computer-mediated communication (other conceptualizations also exist in other fields). Within this description, we focus particularly on Weick's (1995) conceptualization of sensemaking. Accordingly, we draw from the work of Weick, Sutcliffe, and Obstfeld (2005) who define *sensemaking* as the process of "turning circumstances into a situation that is comprehended explicitly in words and that serves as a springboard into action" (p. 409).

According to Weick (1995), sensemaking is a reflexive process that urges people to make sense of the world and how their individual selves work to help in its creation. As such, his theory focuses on sensemaking as a process whereby individuals draw from their personal, social, and cultural lives in

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