

Why Study Disability?

Lessons Learned From a Community Writing Project

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For five years of graduate school, I avoided studying disability because I thought it would require confronting the idea that I have a disability. I was first introduced to disability studies during my master's coursework. I mustered the courage to take the course on disability because deep down, I knew that this thing I was calling a "vision problem" or what the doctors told me is a degenerative retinal disease called retinitis pigmentosa, might actually be a "disability." I left the course feeling stimulated but no less intimidated by the idea of looking at myself in the mirror and thinking "disabled." I resolved that my interest in disability studies was purely personal—it would allow me to learn about my own experiences, but I would do it privately, and I would publicly study something more obviously related to my profession as a writing instructor.

Stephanie L. Kerschbaum corroborates this feeling in her recent article "On Rhetorical Agency and Disclosing Disability in Academic

Writing.” Kerschbaum writes that she, too, resisted suggestions to engage with her own deafness in her scholarship. As Kerschbaum and others have observed, there is a quiet assumption in academics that people who do disability studies either have a disability or are related to someone who does (56). I too made this assumption. I did not want to be doing disability studies just because of my own “vision problem”; I did not want to be seen as doing research that is self-fulfilling; and most of all, I knew that if I did disability studies, then I would really have to come out as “disabled.”

Eventually, though, my personal exploration of disability converged with my professional exploration of writing and rhetoric. When I attended a local support group meeting for people who are blind and visually impaired, I was struck by the stories that people told. I noticed that these stories were unlike the stories I had previously heard about blind people. I had read stories about blind people performing superhuman feats of strength—like biking across the country or scaling a mountain. The stories people told at the support group meeting, however, were about everyday experiences. I wondered what would happen if these kinds of stories circulated outside the walls of the meeting room. I imagined starting a writing group and finding a way to publish these stories. Could everyday stories about disability change public perceptions of people who are blind and visually impaired?

But I immediately questioned myself—do I want to do this just because I am a writing teacher? Would it be purely self-fulfilling? Would I be turning these people into research subjects? Would I be stomping on this organization’s territory? Although I was unsure about the convergence of my two identities—as a university writing instructor and as a visually impaired person—at the end of the meeting, I pitched the idea to the director of the program, and he was enthusiastic. I forced myself to try it.

In this essay, then, I reflect on my experience of starting a community-writing project for people who are blind and visually impaired. My goal is to explain how working with people on their disability narratives has shaped my understanding of writing and rhetoric, and in turn, my understanding of my role as a writing instructor. I draw

upon two areas of scholarship—disability rhetoric and community writing—in order to critically reflect on my experiences.

DISABILITY RHETORIC AND COMMUNITY WRITING

First, I draw upon Jay Dolmage's theory of *métis* to make sense of the ways helping others write about disability has developed my own understanding of language. In *Disability Rhetoric*, Dolmage positions people with disabilities as "*makers* of meaning—rather than as surfaces reflecting the meanings of others, rather than as objects of knowledge" (95). In this essay, I reflect on how learning to see people who have disabilities as "*makers-of-meaning*," allowed me to expand my understanding of language. Dolmage proposes that *métis* can be used as a methodology for understanding disability meaning-making. He defines *métis* as "the rhetorical art of cunning, the use of embodied strategies, what Certeau calls 'everyday arts,' to transform rhetorical situations" (5). *Métis* is further described as cunning, embodied, and sideways moving rhetoric. In order to better understand what I have learned from people who write about disability, in this essay I begin to use *métis* as a lens through which to understand the rhetorical choices that people made when writing about disability.

Second, I reference conclusions from Tiffany Rousculp's *A Rhetoric of Respect: Recognizing Change at a Community Writing Center* to make sense of my role as a university writing instructor working within a community. In reflecting on her ten years of experience with the Salt Lake Community Writing Center (CWC), Rousculp explores what it means to cultivate a "rhetoric of respect" between Salt Lake Community College and the CWC. She explains that in many instances, her own and others' academic notions of what counts as "change" or "empowerment" limited their perceptions of the agency community writers gained through the project. Rousculp explains that she perceived some people to be in need of "a specific revision": "I measured them by how far they wanted to migrate into my environment. My interpretation required them to transgress their current identities rather than for me to pay attention to my own" (91). In this essay, I reflect on how my own identity as a writing instructor evolved throughout the community-writing project. I use Rousculp's concept of "rhetoric of respect" to demonstrate how I began to let my role change as I learned from the writers' own experiences of

communicating about disability. Further, I touch on the tensions I experienced between the personal and the public—between personal and public identities and between personal and public writing—in order to demonstrate how and why I finally decided to study disability.

TRANSITIONING FROM WRITING TEACHER TO COMMUNITY WRITING LEADER

At the outset, I was self-conscious about my role in the community-writing project. As a university writing teacher, I never had to think too hard about my purpose. Because college students are required to write, my purpose always felt clear. In the initial stages of planning the community-writing project, however, I kept asking myself, “Why am I doing this? Do people who are blind or visually impaired even want to write about being blind or visually impaired?” Additionally, I felt conflicted about my own personal investment in the project. On one hand, I wanted the project to be purely personal—my purpose would be to learn more about my own disability identity, and hopefully, I would help others with their writing along the way. On the other hand, I was self-conscious about my personal investment and worried that I would be forcing my agenda upon people for whom writing might have little personal or public consequence.

To avoid going it alone, I applied for a small grant from my university. After receiving the grant, I began partnering with a local organization to solidify a plan. The organization’s outreach coordinator convinced me that there are certainly people who are blind and visually impaired who want to write, but they may not have found an outlet. To align myself with the mission of the organization, they suggested that I recruit participants from across the state. I had originally conceived of the writing group as a group of people sitting in a room together, but when they explained to me that transportation is the biggest obstacle for getting people who are blind and visually impaired together, I had to reimagine my idea of a writing group. Together we concluded that phone conferencing would be the most accessible medium through which to communicate, and we would recruit participants through various low vision support outlets across the state. I sent out two different recruitment announcements. The first described the project as a “writing group” (a well-known term among writing instructors)

and the second described the project as a “statewide storytelling project” with the goal of creating an archive of the life experiences of people who are blind and visually impaired in the state. The first announcement, which called the project a writing group, elicited almost no responses. The second recruitment announcement, in which I called the project a statewide storytelling project, elicited almost thirty responses. It was at this moment that I first realized I would need to continue revising my idea of a writing group by responding to the needs and desires of the community.

Knowing little about disability as an identity, the blind community, or community writing projects, I began by relying on what I know about writing instruction: I know that people need prompts, examples, exercises, feedback, and most of all, praise. I was not so sure, though, whether or not helping people write about disability would be different. Quite frankly, I had no idea what kinds of prompts would be appropriate for writing about disability, and I felt uncomfortable shaping the direction of people’s writing. When I teach personal narrative in college composition courses, I strive to respect the integrity of students’ personal stories, but in my role as a teacher, I do not hesitate to respond to their writing in a way that helps them meet the goals of the assignment. In the community, however, I was not quite sure how much of that “teacher” role I should play. In many ways, I didn’t feel like I had the authority to lead people in writing about disability—I knew about writing and writing instruction, but I didn’t know about disability, and I sure didn’t know about writing disability.

So I decided to begin by asking the writers what they wanted to do. While I had a plan in mind, one not unlike the syllabus for a college writing course, I wanted to find out what the writers’ actual needs and desires were. To my surprise, many of the group members immediately articulated the idea that they find storytelling to be central to communicating their experiences of disability. Many expressed that they see a need for greater visibility of stories about disability. They also described many different experiences with writing and relationships to it: some have published memoirs, others have written unpublished memoirs, others write for work or for

their church, others blog, and some have never written for work or pleasure at all.

Feeling perplexed by how I would accommodate such a variety of experiences, I defaulted to imagining the community-writing project as a college writing course. I reverted to the plan I know best. I introduced the idea of drafting. I supplied a copy of Anne Lamott's "Shitty First Drafts." I started encouraging writers to give feedback. I supplied a "best practices for feedback" tip sheet. I asked writers to read their writing aloud. I gave short lectures about "showing versus telling" and the importance of communicating a message in a story.

After a few weeks, though, I started to feel like something was amiss. It wasn't the same feeling that I get when I sense that my students haven't done the reading. I sensed that something else was going on.

RENEGOTIATING THE AGENDA

I soon realized that I would need to adapt my agenda, on both a conceptual and logistical level. When I asked a group of people who are blind and visually impaired to read their writing aloud over the phone, I quickly realized I would have to alter my strategy. Many of the writers were using screen readers so they couldn't look at the words on the page—they could only listen to them—and others were using screen magnifiers of various kinds, so reading aloud on the spot was not the easiest task. Because I wanted to stick to my strategy of having writers listen to each other's writing, I asked the writers if I could read their writing aloud for them (although I am visually impaired, I can read comfortably off a computer screen with specific accessibility settings). They agreed, and we found that this strategy was helpful for giving feedback over the phone. By reading their writing aloud in the moment, I was able to help the writers refresh their memories of each other's stories.

Later, I offered other pieces of advice about how to give feedback on writing, like "be specific," "point to specific pieces of evidence," and "direct the writer to specific lines and words." Again, I quickly realized that this kind of specificity is not always possible for many of the writers when we are giving feedback over the phone. I realized

that when you are listening to writing rather than looking at it, it is much more labor-intensive to have to recall specific lines and words. Over time, we naturally shifted from giving feedback on the phone to giving feedback over email because it allows for more time to compose feedback immediately after listening to or reading the drafts.

I also had to figure out how to give feedback that would help writers tell their stories in the ways they wanted to tell them. Of course, I had encountered this challenge before when teaching undergraduates, but I felt even more of an obligation to respect the integrity of these writers' stories. I felt especially responsible because I was working in partnership with a local organization—I did not want community members to think of me as the know-it-all academic. I was very self-conscious about my role as an insider/outsider. I do share the experience of being visually impaired, but I believe that I have had a relatively privileged experience with disability—I have received the accommodations I need to study and work, and I am younger and far less visually impaired than many of the members of the writing group.

But when I realized that the participants did want to learn from me, I decided that the most useful thing I could teach them is what I know about how to tell a story. I noticed that in their initial drafts, many of the writers were not doing what I considered “storytelling”—they were writing about their experiences, but they were speaking about them in general terms, rather than by focusing on specific moments and events. This is something I see in student writing all the time, and I tell them things like, “Show don’t tell” or “Slow down” or “Focus on specific moments.” When I began using this language with my writing group members, I made sure to tell them that I am not giving this advice because of some arbitrary textbook rule—it is because I believe that we can communicate in more powerful ways if we tell stories that allow readers to experience our moments and our lives, if we let them into our realities.

Eventually I began to realize that my ideas about storytelling might change as I learned more about what it is like to communicate about disability. Soon the writers were teaching me about how to tell a story.

LEARNING TO NARRATE DISABILITY

As we continued to compose our stories, I became more and more aware that my writing pedagogy wasn't holding up as well as it does with undergraduates. As I explained above, I advised writers to focus on specific moments to tell more powerful stories. I noticed that some writers were making these changes in their writing, but overall, many of the writers continued to write in what seemed to me like general terms, focusing on a specific dimension of their experience like cane training, grocery shopping, or self-advocacy. Many of the writers opted to be more instructive and pragmatic than dramatic and emotional when I had advised them to focus on specific moments and details in order to let readers into their experiences.

It started to become clear to me, though, that while I could teach these writers about how to tell a powerful story, they were beginning to teach me about how to write about disability. In retrospect, I see their writing processes as processes of exercising *métis*, or cunning, embodied, sideways moving rhetoric—a rhetoric that attempts to work with, through, and against myths and stereotypes. In the following section, I will use a couple of examples to demonstrate how the writers began to teach me about what it means to narrate disability, and I will end by explaining how these instances shaped my understanding of my role within the project and my relationship to disability studies as a scholar of writing and rhetoric.

A Few Examples of Métis in Action

I'll begin with one of my own writing challenges as a way to demonstrate the complex task of narrating disability. I began the writing group with a desire to communicate about the perspective I have gained, rather than lost, from the experience of losing vision. Andrew Solomon's book *Far From the Tree* inspired me to write about this aspect of my experience—Solomon describes his interviews with many parents of children with various disabilities who articulate the enlightenment and happiness they've gained from parenting special needs children. When I explained my story idea on the phone to the writing group, they all seemed to agree and understand the sentiment I was getting at. When I sat down to write the piece, however, I felt like it wouldn't be a simple task to communicate a feeling of gratitude and happiness. I knew I had to *show* rather than tell readers about

the feeling, but I was stymied by the thought that disability is never considered a positive or happy thing. I was well aware that the idea of disability, especially the idea of vision loss, scares people. I worried that those fears would prevent my readers from understanding and believing my point about the affordances of living with a disability, so I ended up abandoning the topic. I had no idea how to write against or through the pervasive cultural narratives of fear and despair that shape perceptions of blindness and disability.

But other writers have taught me some navigation strategies.

One writer wanted to describe what she calls “the bubble of isolation” that surrounds people with disabilities. She expressed that she wanted to use her story to instruct people on how to socially approach people with disabilities, or as she puts it, “break bubbles.” When attempting to turn the story into a short radio piece, she received feedback from a producer asking her to focus more on emotions and less on directives. The writer insisted that she needed to use directives because her experiences of being blind since birth and having been a clinical psychologist have taught her that directives help people figure out what to do in stressful situations.

I was fascinated by this interaction because I could have likely given this writer the same feedback—as a writing teacher, I often suggest that students focus on specific moments and let readers into those moments, a move that often involves engaging emotion. While this writer’s story does focus on a few specific moments and does describe emotional reactions, she frames it with directives that instruct readers on how to approach people with disabilities. When the producer insisted that the writer use more emotional appeals than give directives, the writer stood her ground and explained why she thought directives would be more effective than emotions at changing behavior. The writer explained that from her experience of being blind since birth, she knows that clear directives help people change behavior and that engaging emotions, while moving, is not as effective of a strategy for moving people to action. Even though the producer stood behind her theories about the pivotal role of emotion in radio storytelling, they met somewhere in the middle and finally recorded the story for broadcast.

As an observer of this interaction, I was fascinated by the deep-seated conflicts that emerged from these two approaches to communicating disability. What is more, I admired the writer's use of a rhetoric that departed from my own ideas about what makes a good story, as well as from the radio producer's own convictions about what makes a good radio story. Her rhetoric was in fact cunning—she deliberately chose to not make her story primarily emotional because she knew that an overly emotional story about disability could perpetuate stereotypes and she doubted its effectiveness in changing behavior. While I had initially read her drafts as “needing to focus on more specific moments,” she later showed me that her directives and general language were intentional—she knew from her own experience of being a blind person that this is the kind of rhetoric she feels is necessary in order to cause change. This is an example of one instance in which my ideas about what counts as change or empowerment, as Rousculp puts it, were challenged. I began the project with the assumptions that people will want to write emotional stories, that writing emotional stories will result in empowerment, and that those stories will result in change, but this incident revealed to me alternate ways the writers might gain agency through the project.

Another writer wanted to write about going for walks by herself. In her initial drafts, she described one walk in which she has a near-collision with a bicyclist, gets lost, and asks for help from the same woman she ran into on a previous walk. The story was lighthearted, cheerful, and humorous, but from my perspective, it lacked narrative arc and a take-away message. I encouraged her to include more information about her vision loss, what this walk taught her, and how this walk fit into the trajectory of her own understanding of her disability (in other words, I asked her to write a book instead). She revised the story, taking some of my recommendations into account, but once again, I was left feeling like something was amiss. I was making suggestions in the same way I do with students, and I understood that these writers are more mature, and some of them are more experienced writers, but it felt like something else was happening in these exchanges. I could tell that these writers were making deliberate choices but not the ones I originally hoped they would. Numerous times this writer had emphasized her belief in the value of humor—she approached many of our conversations with a sense of humor, so it did not surprise me that she wrote her story

with the same tone. While I have yet to ask this writer about her rhetorical intentions, I now see her use of humor as cunning—her lighthearted, upbeat tone is striking and unexpected, and the sense of humor she uses to approach and interpret the events of her life run contrary to narratives of loss and despair. Once again, I would not have originally seen humor or lightheartedness as a means of gaining agency through writing, but it has become increasingly clear to me how important it is to let individuals decide how they will exercise agency.

Further, these experiences caused me to revise my idea of a writing group. At first I would begin our phone conversations by discussing a specific writing strategy, but we would quickly depart from the subject of writing. Group members would launch into conversations about their personal experiences with stigma, technology, filing lawsuits, or whatever was going on in their lives relative to blindness. At first, I saw these conversations as tangential—I scrambled to find ways to bring the conversation back to the writing task at hand, but later I realized that connecting on these topics was serving as a means to discuss disability communication. Our conversations often focused less on the mechanics of telling powerful stories than they did on what kinds of rhetoric might be useful for telling our stories in ways that challenge stereotypes and cultural narratives. Now we spend our conversations connecting on issues and experiences relative to blindness and visual impairment, and after the conversation, I email a list of topics that were discussed and encourage writers to claim those topics for future blog posts. Many writers have expressed that they almost always leave the conversation with a story idea in mind. In other words, I shifted from imagining our phone conversations as a venue for talking about writing to viewing our conversations as a means of generating story ideas and rhetorical strategies.

WHY STUDY DISABILITY?

From this experience, I've learned why, as a composition and rhetoric scholar, I would study disability. Yes—it is true that part of my motivation for starting the community-writing project was because I am disabled, and yes, it is true that the experience has taught me a lot about myself. But what is more significant to me is that it has

taught me about language. Whereas I once declared, “We just don’t have the language to talk about disability in daily life” in my disability studies course, I am now beginning to understand why I felt that way, and I have learned that my hunch was not unfounded. As Dolmage articulates, we have failed to see people with disabilities as makers-of-meaning rather than as objects of meaning:

From antiquity to the very present, disability has been seen as something simple to trope and frame. In this way, rhetoric has been used to mark out and stigmatize disability, thus providing us with limited means of interpreting and understanding the role of people with disabilities in rhetoric and in society. (83)

When I kept repeating my comment in class about the difficulty of communicating about disability, I may have been avoiding outing myself as disabled, but I also may have been steeped in a kind of rhetoric that “marks out and stigmatizes” disability. I was not aware how disability can be “the very possibility {and concurrently the uncertainty} of human knowledge” (124). This service project has taught me about the complex challenges of finding words to describe an embodied experience, particularly one that is so overdetermined that the most common linguistic labels like “blind” or “visually impaired” ignite fear in the minds of readers and listeners. It has taught me about the challenges of writing through, with, and against large cultural narratives of despair, dependency, and deficit. It has taught me how a cunning, embodied, sideways moving rhetoric can shirk expectations and challenge norms. Most importantly, it has taught me to reimagine what it means to tell a powerful story.

It has also taught me to reimagine my role as a writing instructor, both within and outside university classrooms. As I have articulated, I learned to let go of my ideas of what counts as change or empowerment for community writers. I now realize that conventional ways writing instructors conceive of helpful approaches to the writing process (I.e. reading aloud, providing oral feedback) might not always be the most accessible means of engaging in the writing process. I now know that I should strive to provide as many options for engaging, and sometimes those options may not be immediately apparent. Further, my own life experiences do not suffice as the basis for understanding

how storytelling, or rhetoric, works. Each individual's life experiences shape the way they approach communication, and teachers should facilitate exploration of those methods, rather than restrict them. And finally, I learned that if I truly listen to writers' own goals, rather than relying on my own plans and priorities, I might learn more about writing and rhetoric than I knew before.

And yet there is always more to learn. I am now interested in the process of learning how to write and communicate about disability. I am interested in how people with disabilities learn to approach the task of changing attitudes and behaviors. How do people with disabilities learn to make rhetorical moves? How do we learn to exercise cunning rhetoric in the face of dominant narratives? How do we learn to move sideways, against the grain of dominant narratives while also maintaining forward motion? How do we learn to use emotion without overdramatizing our experiences? My hope is that questions like these will expand our understanding of language and its abilities and inabilities to convey human experience. Dolmage writes that because

meaning itself can be metaphorized as immobile, 'crippled,' delayed, in need of assistance... metaphor should be seen as the space within language where the breakdown of meaning is addressed not with correction or seamless substitution, but with something else: where the holes in language are plugged with squares and triangles, or where we recognize the inaccessibility of all meaning-making. (103)

It is those squares and triangles that I want to know more about. I want to know how those squares and triangles turn into powerful, conversation-changing stories. I believe that knowing more about the accessibility and inaccessibility of language will make me a better composition and rhetoric teacher—it will make me better at helping students plug their holes with squares and triangles. I now see that studying disability is one way for me to get there.

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