**From Disclosure to Accommodation: A Road Full of Obstacles**

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At Purdue we have a new academic center called the Center for Research on Diversity and Inclusion. Its director was recently asked, why do you include the words diversity *and* inclusion—if there’s diversity, then there’s inclusion! The director answered that no, there could be diversity in an institution—an array of people of all identities and backgrounds *present—*without true inclusion, for example if many people are marginalized or silenced or their work undervalued. So diversity does not imply inclusion. But as I pointed out, true inclusion *does* imply diversity, because diversity is a fact of human life. If an institution is truly inclusive, then the wide diversity of human beings in it will be manifest. This applies to my life as an English professor at Purdue—I am present on campus, I am tenured, and as a deaf woman, I therefore contribute to the diversity of the institution. But I want not merely to be present, but to be included. And to be included, I need some accommodations.

Before I can receive accommodations, people in positions to grant them need to know, accept, and understand my disability. In my efforts to disclose my deafness and seek accommodations, I experience two main obstacles: either a refusal to believe in my disability or an overemphasis on or even exploitation of my disability.

Because I am a culturally Hearing, gradually-deafened adult, my disability is not only invisible until I disclose it, but seems to keep returning to a condition of invisibility. This dynamic is an integral aspect of compulsory ablebodiedness; as Robert McRuer notes, ablebodiedness “still largely masquerades as a nonidentity, as the natural order of things” (1). The flip side of this “natural order” is that absent a clear marker of disability, the assumption, made unconsciously, is that someone is nondisabled, occupying the “natural state” of human existence. Whereas people with visible disabilities are made invisible in many damaging ways, people with invisible disabilities are categorized by normates as normates. Like the type of casual racial passing in which Nella Larsen’s Irene Redfield engages, where she simply goes places darker-skinned African Americans cannot, being taken as a normate can obviously confer benefits. But at the same time the refusal to see the disabilitysends the message, we accept you as long as your disability remains invisible—we would not accept you if we saw you *as* disabled. This ties in with Patricia Williams’s distinction between being visible and being recognized (qtd in Siebers, article version of “Disability as Masquerade,” 20, fn6). For culturally Hearing deaf or hard-of-hearing people, it’s hard to find *recognition* and acceptance at the same time.

Moreover, having to repeatedly disclose one’s disability in an effort to get recognition or accommodation can be, as philosopher N. Ann Davis writes, “an awkward and thoroughly unpleasant undertaking.” Davis argues that “people whose disabilities are invisible are regularly put in the position of having to challenge the adequacy of our society’s human paradigm head on, and of having to confront the wall of denial that surrounds and upholds our subscription to this paradigm” (205). Davis’s conception of our “human paradigm” bears a close relationship to the idea of compulsory ablebodiedness more commonly used in disability studies.

My position has some parallels with the position of a lesbian femme as Ellen Samuels discusses it. While Samuels points out the dangers of over-analogizing, there do seem to be some particular aspects of my position that parallel the lesbian femme. First, people in the minority group (big-D deaf people and more visible or butch lesbians) see us as selling out to the mainstream world. Using the phone, for example, no matter how loud the volume, can mark one’s cultural identity as hearing and prompt some culturally Deaf people to dismiss me from their ranks. Like the lesbian femme, a hard-of-hearing person can be made to feel like she fits neither in the mainstream (hearing/heterosexist) world nor in the minority (Deaf/lesbian) world. Brenda Brueggemann aptly writes, “I couldn’t be deaf any more than I could be hearing. I was hard-of-hearing; and therein I was as confused and displaced, in either Deaf or Hearing culture, as this multiply-hyphenated term indicates” (*DS Reader* 210).

Second, disclosure is liable to meet with disbelief or dismissal. The lesbian femme gets, “you’re not really gay,” or maybe “it’s just a phase.” Hard-of hearing and small-d deaf people get a similar response when people say, oh, no, you’re not deaf, you seem to hear me just fine. In both cases, people think they are complimenting us by refusing our statement of difference, the way it’s a compliment if one’s boss refuses one’s letter of resignation. No, they imply, you cannot resign from the group of us sexual or physical normates—you’re one of us! But not only does this kind of well-meaning dismissal of the disclosure refuse us *recognition*, but it also serves two other functions. First, it makes accommodations impossible. As Samuels notes, many people with invisible disabilities “write of being denied benefits and accommodations because their nonvisible disabilities are perceived as minor or imaginary” (246-7). And second, it confirms the negative valence of disability. We immediately recognize this dynamic in the case of race—when I was a young teenager, I cringed when a white friend told a mutual friend who was African American that to him, she was “just like any white person.” He meant that as a compliment. But even as a thirteen year old, I could easily hear in it the denigration of blackness. Most people in our culture, though, do not hear in a sentence like “Oh, I don’t think of you as deaf” or the “you’re not really deaf” a denigration of deafness—or if they do, they don’t mind. Since disability, they think, is universally considered a negative state, of course anyone would be happy to be classed with the normates, to have their resignation from normalcy refused.

Each invisible disability, of course, has its own characteristics. I want to pause here to talk about the particular invisibility of being hard-of-hearing or small-d deaf. One of the reasons hearing people say things like, “but you seem to hear me just fine” is because they have no idea how much meaning gets expressed visually and how far, with substantial effort, a deaf person can take a little sound perception in a one-on-one conversation in a quiet space. This is not their fault! ☺ It’s just that they haven’t experienced being deaf and so they tend to overvalue hearing. Georgina Kleege points out that most blind people know a lot more about being sighted than sighted people know about being blind (*DS Reader* 522). It’s similar with deafness. Because hearing people don’t understand that one doesn’t need to hear every tiny sound that makes up an utterance to understand the utterance, they erroneously assume that deaf people who communicate fairly well verbally must actually hear quite well—much better than they say they do.

But I don’t want to make it sound as if being deaf presents no problems in communicating with hearing people. It emphatically does, and these problems are much worse in groups. Probably all hard-of-hearing people have experienced the embarrassment of making a comment that is, as Brueggemann puts it, “off topic, three steps behind, completely out of sync with the others” (*DS Reader* 216). My point is simply that hearing people cannot tell how much deaf people can hear by observing how well they seem to cope with a one-on-one conversation—and even in groups, they cannot tell how much a deaf person is hearing, how much she is speechreading, and to what extent she is passing. Another thing hearing people don’t typically understand is the effort deaf people put into communicating orally. When my hearing friends are surprised to learn that my hearing loss is classified as severe in a few pitches and profound in several pitches, they are confirming that they have no idea how hard I work to make meaning out of limited information every time I communicate orally with them.

To return to the two problems I face when I disclose and ask people to accommodate me: I have regularly had my disability dismissed, and one salient example is my experience at conferences during Q&A. As the panel begins, either I or the panel moderator will announce that I’m hard of hearing or deaf (it doesn’t seem to matter which word is used) and that they will be handing around the mic of my FM system. Invariably there is at least one person who says, “oh I think I can make myself heard” and refuses the mic. How dare these people assume they know what I can and cannot hear? But more importantly, what gives them the idea they can know this? I have to conclude that it’s because I speak—I am culturally Hearing--and so they do not *place* me as deaf.

To induce people to view me as deaf, it seems I would need some sort of prop. Samuels describes two blind women who carry white canes not because of their functionality for mobility, but as indicators to others that they are blind (240). Tobin Siebers describes an airline gate agent who wouldn’t let him board early unless he was in a wheelchair (96). What could my prop be? Joseph Grigley suggests red hearing aids (Siebers 102). I already have purple earmolds for my hearing aids and have kept my hair very short for most of the last ten years, but people still didn’t notice or *place* me as deaf. Would I need to sign to my colleagues at the same time I talk to them for them to accept my deafness? This would be quite a disingenuous form of masquerade since they wouldn’t understand the signs and, although I have basic competence in ASL, I am not fluent.

This phenomenon, in which others refuse my resignation from the group of normates, is best described by Megan Jones in her *Ragged Edge* article: “Many people are more comfortable relating to me and accommodating me if they can be absolutely certain that I am who I say I am, a deaf-blind person. And they are not absolutely certain that I am that person until I bump into a wall or shape my hands into what is to them an incomprehensible language. In other words, I *must make myself completely alien to these people* in order for them to feel that they understand me” (italics added). Jones’s point about being rendered completely alien is ironic, but it is true that people seem to need to categorize someone as *either* deaf or hearing, either “other” or same; and if you seem “same” enough, then that is all the info they need.

On the other hand, I sometimes face very different obstacles when I disclose and seek accommodations, when colleagues overemphasize or exploit my disability. A couple of examples from my service on my department’s large promotion and tenure committee will illustrate these.

Some of the time our primary committee, as it’s called, meets in a room that’s fairly good for me, with tiered tables arranged in a u-shape. I can see many of my colleagues and speechread them as they speak. I do request CART for these meetings, but because English professors tend to speak in long, convoluted paragraphs, the CART provider is almost always significantly behind. So I try to listen and speechread as much as I can, and rely on the CART for backup. But there are always a few people whose faces are completely blocked by those in front of them, so at one meeting, I asked my department head to request that everyone try to give me a line of sight to the person speaking. Of course, in accordance with the invisibility of deafness, everyone forgot about that once the discussion began. So at the break, I went over to the few people whose heads were blocking those behind them and said, if so and so speaks, would you mind just turning slightly—the chairs swivel—so that I can see her? They all said sure, and this time, having been singled out, they remembered. When the designated people spoke, three different people made a point of LEANING WAY OVER, calling too much attention to their “accommodation” and making the whole thing appear ridiculous.

In another situation, [description removed for web publication to protect the privacy of those involved].

The deaf-blind poet and writer John Lee Clark has discussed these issues with me on email, and his view is that if you’re similar to people, they can’t accept that you’re different at all. But if you do not *speak*, if you remove yourself from hearing culture, they are willing to make much bigger accommodations—such as writing down what they want to say to you—than the accommodations they were being asked to make when they viewed you as similar to them and which they were *not* willing to make. Megan Jones’s contention that she must “make [herself] completely alien to these people in order for them to feel that they understand [her]” helps explain this phenomenon. If you are seen as “same” you have important privileges. But then you are not *recognized*, you are not understood to need any accommodations, and the negative valence of disability persists.

The problem, then, is the need for categories. In my disability studies classes we always discuss the benefits and drawbacks of both universalizing and minoritizing conceptions of disability. Universalizing views can undermine the specificity of disabled people’s experiences and fail to take into account the oppressive systems that make access to our common life difficult or impossible for disabled people. But for the purpose of getting people to understand that one needs accommodations to access spoken language even if one does speak oneself, the universalizing view, the view that any of our abilities or functions can all be placed on a continuum, is more effective. For example, my mother has good hearing, but she is easily distracted, so she can’t “hear”—attend—over background noise. We accommodate this “need” by reducing background noise when we are with her (or trying to, because my two children tend to be as loud as a troop of monkeys). Each individual has his or her peculiarities in carrying out the functions of daily living; none of these ought to have to be categorized strictly as disabilities to be worthy of accommodation—or to put it the other way, everyone has disabilities of these sorts in some area or other, and each of those deserves accommodation by those around them.

In *Mad at School,* Margaret Price suggests language for syllabi to let students know they can ask for accommodations. The language is meant to be directed at all students, who all have different learning needs and priorities. She suggests saying something like, “I assume that all of us have different ways of learning, and that the organization of any course will accommodate each student differently…. Please communicate with me as soon as you can about your individual learning needs and how this course can best accommodate them” (90).This language works toward a universalizing view of disability, dismantling the divide between “normal” students and students with “special needs.”An awareness and acceptance of the wide range of human variation rather than an insistence on categories of able and disabled would go a long way toward diffusing the problems that we in-betweens, we hard-of-hearing, we with invisible disabilities, experience when we disclose our disabilities and ask for accommodations.

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