

Tumbled Identities: Negotiating Invisible Disabilities and Sexual Orientation

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Introduction

The purpose of this paper is to explore the interconnections between invisible disabilities and sexual orientation which came out within the context of a larger research study on the construction of identity of women with LD. The authors of this paper all participated (either as co-researchers or participants) in the original study which was a participatory qualitative study conducted electronically. In this paper we will first review methodological issues, then explore electronic spaces as a unique site for identity construction, and, finally, address portions of narrative illustrating the interconnections between invisible identity categories.

Methodological Issues

The choice of methodology for this work was driven by a desire to conduct ethical research and to offer something tangible back to those participating in the research process. In this study, our collective identities placed us as outsiders in some ways, insiders in others: the web of subjectivity is rarely reducible to the simple categories of insider/outsider. I (Beth) do not identify as having a disability; however, I believe that participatory research has the potential to bridge differences. As Audre Lorde (1984) argued, it is not difference that separates us, but rather our inability to talk across difference. Further, for M.M. Bakhtin (1986), difference is seen as adding a creative tension - one that is useful in producing more complete understandings.

Participatory models create an interesting tension in the research process - to re/present people capable of answering back while retaining a critical lens is sometimes difficult. The intention of this project was to create a space for dialogue, where connection

across difference would lead to greater understandings than could any one voice or perspective. In this way multiple voices and subjectivities were seen as equally valid; rather than coming to consensus on issues, different viewpoints were allowed to coexist.

Our roles in the study were that of participants and co-researchers. We communicated electronically with eight other women with LD over the course of 2 months. As co-investigators we collectively framed the questions for the study, participated in the data analysis, and now collaborate in the dissemination of results.

I (Beth) disagree philosophically with some recent scholars, such as Drake (1997), who view legitimate roles for the non-disabled in very narrow, essentialist, and

overly deterministic ways. Instead, I draw on feminist scholar Linda Alcoff (1995) who acknowledges that personal location is epistemologically significant, but not determinant. As Leslie Bow (1995) contends, "critical authority is based on an awareness of the self-in-the-world," but this does not undermine or forgo an ability to see social structures that exceed the self (p. 49). Likewise, current scholarship by Butler (1990) and Sedgwick (1990), for example, trouble the notion that knowledge or selfhood are transparent or that experience automatically yields critical consciousness.

Finally, I do not believe that the only contribution of the non-disabled is flight, or, as Alcoff (1995) writes, to "move over and get out of the way" (p. 100). A retreat response allows the non-disabled to avoid both criticism and responsibility. Silence, however, is every bit as political as speaking up or out, and only those with privilege can afford such non-action. To not act is to accept and help sustain the status quo. Instead, a self-critical approach involves: analyzing one's impetus to speak; interrogating the bearing of one's location on what can be known; taking accountability and responsibility; remaining open to criticism; and attending to the effects of knowledge claims on the broader context (Alcoff). To Alcoff's list we would add working collaboratively.

Influential to this project is the work of Corbett (1994), Field (1993), Shakespeare (1995), Tremain (1996) and others who explore issues of sexual orientation and disability by either complicating unified and singular notions of the self, or working toward articulating connections within a minority group identity politic.

Email and Cyber Identities

An important aspect of this study explores how issues of identity are made more complicated in electronic spaces. For example, some disabilities, such as learning disabilities/dyslexia which are typically invisible, are made more visible in electronic spaces. Likewise, more visible disabilities can be rendered invisible in electronic spaces. Thus, this interplay between hiddenness and visibility changes the 'rules' of disclosure. However, as framed by both Butler (1990) and Sedgwick (1990), the ultimate rule of disclosure about sexuality maintains that coming out recreates rather than deconstructs the closet. Thus, the disability and sexuality closets remain intact both in electronic and face-to-face communities, albeit differently. In both kinds of spaces the dominant group maintains its position as the taken-for-granted norm by which all others deviate. Paradoxically, this site of deviance, out of necessity, also becomes a location for political agency and identity. Using language can likewise be strategic. Claiming labels of difference, like cripple or queer, which have been devalued by the dominant culture can be a transgressive act and a rallying point of resistance.

Another paradox of electronic space is that although one can transgress geographic boundaries, other kinds of boundaries may be emphatically enforced, either by official or unofficial regulation. Thus, electronic communities, often formed around specific topics of interest, serve to recreate rather than transform essentialist and reductionist identity categories. Such strictly imposed boundaries in electronic spaces may be an attempt to compensate for the lack of visual or cultural cues inherent in physical communities that clearly marking others. Certainly a review of disability related lists reads like the DSM-IV list of diagnostic categories!

Likewise, discussions which stray from stated purposes of particular electronic lists are often seen as 'off topic' or 'irrelevant.' Individuals who complicate the singular focus of a list by demanding recognition of multiple subjectivities are often not tolerated by those 'policing' the list. Therefore, a particular risk of disclosing multiple identities in electronic spaces includes managing the resistance of those occupying normative positions who fail to see the interconnections between oppressions, or to understand identities as multiple. In other words, enforcement of the status quo is managed as efficiently in electronic spaces as in physical spaces, and possibly more so because 'ownership' of electronic spaces is still a relatively undefined concept. 'Flame wars' often erupt when conflicting notions of appropriate discussion content are debated. This push and pull over expanding or limiting the scope of discussion often results in threats to an individual's sense of belonging to a certain electronic group (or claimed cyber-identity) demonstrating again how identity is contested within electronic spaces.

Thus, although electronic spaces are often assumed to open new possibilities, to expand and allow play into our notions of identity, they simultaneously place restrictive borders around the self. As Barglow (1994) suggests, the electronic world is simultaneously empowering and disempowering, merging and segregating. It can create new forms of community, but also heighten depersonalization, alienation, fragmentation, and invisibility. Thus, electronic spaces seem to offer the ultimate playground for the self, where individuals can try on different genders, races and bodies, but some bodies and some brains find electronic travel more difficult even with advances in technology.

Carolyn commented, "Technology once took away my LD; now it's back." She explains:

When I first enrolled in college, I depended on technology/software to take away my LD. I used spell check, grammar check, and word prediction software. Now I also use voice input and screen reading programs. By using these programs and by having an overall interest in technology, I have become somewhat of a 'techie.' However, I am now faced with the dilemma of people wanting to communicate with me through email and on-line chatrooms (and both are a big part of my current job responsibilities). I have not been able to use my AT (assistive technology) effectively in these environments and this is very frustrating. I am suddenly very aware of my LD and find myself needing to disclose to everyone/anyone with whom I have electronic contact. Whereas, if I meet the same people face-to-face or over the phone, disclosure would not be necessary.

In electronic spaces text becomes the body; therefore, how one writes becomes how one is seen. Literacy, then, replaces body ideals as the benchmark of attractiveness. Therefore, standards of beauty still apply--but those who are highly verbal, quick witted, and can type fast and accurately are the "beauty queens" of the cyber world. As Carolyn writes, because of LD "my first impression in electronic spaces is NOT my best!"

Speaking Invisible Identities

The final portion of the paper highlights some of our discussion that related to LD

and sexual orientation. Our purpose in sharing this discussion is to illustrate how by exploring the multiple connections across difference through a dialogic interaction, we attempt to explore identity without falling into a trap of reducing identity to categories or labels. As the following discussion demonstrates, this process is complicated and not without conflict. One of our earliest discussions within the larger study dealt with being multiply situated in terms of identity. We believed that attention to and recognition of these multiple identities from the start would lessen any tendency for reductionistic or overly simplistic representations of selfhood.

In our discussions, several themes emerged that parallel central concerns in recent disability and sexuality scholarship: a) the importance of naming or defining the self; b) reclaiming language and the terms of representation, c) the complications of disclosure; and d) the social pressure to pass. The following discussion inspired the topic of this paper.

BJ: "I think the experience of being separated out from the average is magnified by each way in which you are separated out. [Which is akin to what black feminists have called 'double jeopardy' (Beale, 1970)]. Being a lesbian, 'different' is something I have always felt and the two issues of sexual orientation and ability to learn have been tumbled up together in terms of identifying for myself why I feel 'different.'" Paula: "I've only recently come to recognize all these invisible components of my makeup as distinctly identifiable [yet inseparable]. I guess it came into focus three years ago when I moved across country and into a completely new community. I recognized that I had a wonderful chance to construct the person I wanted others to recognize as 'me.' I had to make some conscious decisions about disclosing my LD circumstances, my lesbianism, and my chronic fatigue -all invisible characteristics that really have an impact on my identity... It was only recently that I have been able to look back and see [how these] invisibilities collided and nearly made me an invisible causality." BJ: "I sense that an awful lot of who I am, how I make decisions, how I interact with people, and how I feel about myself have been shaped by the experience of not being seen." Paula: "I had assumed much more of my identity as having come out of my experience as a lesbian than any other facet of myself. Recently, I've realized that my LD shaped more of me than I'd understood." "Perhaps the identity we get from being lesbian is bolstered by our growing and overt community... Whereas the LD issues seem to me to be more like other invisible identity traits which, as yet, have no overt community - no 'cultural heritage'... and we each have to forge our own direction."

These sections of text illustrate the ways that, according to Audre Lorde (1984), differences cannot be separated. These voices also point to another discussion among the group on the importance of naming the self. Participants supported the idea that identity is both socially and personally constructed--that selves are claimed and made within social contexts. Creating a space where people can dialogue across differences can be compli-

cated. Pearce (1994) cautions readers of Bakhtin not to misunderstand his notion of dialogue as simply being a conciliatory exchange, because all dialogue is infused with power relations and multiple voices.

Additionally, an important aspect of narrative analysis as a methodology is to listen not only to what is said, but what is not said - to gaps, silences, or even contradictions in a narrative (Chase, 1996). One example of a silence or gap in the narrative had to do with race. Very few participants who were white mentioned race in their introductions. This is not surprising, however, because aspects of identity within the norm often become transparent. As Roman (1993) contends, "white culture is the hidden norm against which all other racially subordinate groups' so-called 'differences' are measured" (p. 71). Likewise, most people who are not disabled do not consider ableness as part of their identity - ableness, like whiteness, is taken-for-granted, often not consciously considered to inform identity.

An aspect of difference that was questioned was sexual orientation. Two of the women who were heterosexual commented on the number of lesbian participants, one who mistakenly thought that she was in the "hetero-minority" and another who believed that the recruitment process might have been biased resulting in a nonrepresentative sample. This was the only aspect of identity that was questioned in this way, even though a disproportionate number of women were white and had been diagnosed with Chronic Fatigue Syndrome (CFS).

As Paula noted in her closing comments:

"Being women with learning disabilities was the constant here, and our other similarities were striking. Yet, the item of difference that was picked out was the gay-straight theme. Perhaps the visibility resulted in some discomfort of queer disclosure because gayness is usually an aspect of identity that remains non-apparent."

BJ: "I remember the comment about the hetero-minority. I believed it was very appropriate [to discuss sexual orientation] because so much of being gay and having learning disabilities involves struggling with 'hiddenness.'"

It may be difficult for individuals who are in the dominant group to understand why aspects of identity outside that norm are salient. Moreover as a researcher (Beth) my own identity as a lesbian may have contributed to participants feeling okay about discussing sexual orientation. The issue of disclosure was an important issue for many of the participants, and they spoke not only of breaking silences, but of having to deal with attitudes of disbelief and denial from others when they did choose to disclose.

Paula: "Disclosure creates a feed-back loop and the impact of a negative response to coming out - regardless of how secure one is - will be felt. Since I came to understand myself as 'different' due to my LD long before I saw that I was 'different' due to being a lesbian, I believe my internalization and way of dealing with outing myself in the LD arena patterned my response to coming out as a lesbian. In both cases, I chose to

"pass" whenever possible...even though I knew who I was/am and was comfortable with this reality."

"Now I'm aware that disclosure is a conscious decision & I weigh the relative costs/benefits to my choice at the time. As a mentor/role-model in a college setting, I'm finding myself coming out all the time - both with LD & being a lesbian. The students seem to be exceptionally needy for images of someone who's alright in the world even though they're different."

Other participants spoke of their experiences with LD as being framed by isolation and shame of having a difference that is not seen, understood, or even believed by others. They expressed a difficulty in forging a positive sense of self against a backdrop of silence, invisibility, and oppression. In light of this risk of negative reactions by others, the decision to disclose necessitates a juggling of personal and political realities. Paula writes that "choosing to risk negative personal outcomes" of disclosure is continually weighed against the perceived political gains or the importance to the larger community. She writes that often behind disclosure is a "sense of political responsibility to the larger good."

Another negative outcome the group associated with passing was exhaustion. Many women spoke of having to constantly monitor themselves - watching for "LD-type" mistakes in a variety of daily tasks. Lesbians, who for a number of reasons choose not to disclose, also speak of having to monitor their language (i.e., pronoun usage). Excessive self-monitoring seemed to cause a cycle: beginning with perfectionism and fear of making mistakes; resulting in almost constant anxiety about being found out; and ending finally with exhaustion. This cycle also resulted in some women feeling hyperfocused on themselves - sometimes at the risk of appearing egocentric to others. Women who have multiple invisible identities wishing to pass may find themselves perpetually caught in this cycle and be at greater risk for developing depression and anxiety-related problems.

Conclusion

It became clear from the beginning of the study that none of the women could be defined by only one subjectivity, nor did they see themselves as such. Even within self-identified categories there were many overlaps and connections with other categories. As stated, it can be difficult and uncomfortable to connect across differences; yet, it is this potential in connecting across difference that is at the heart of dialogism.

In closing, Paula offered the following metaphor to illustrate the impossibility for any identity categories to, as Bakhtin (1986) contends, "capture the self." She writes:

"I still think of my identities as being tangled together. Another possible metaphor is that of a color chooser on a computer... if you've got it set to thousands of colors - you get a circle with thousands of varieties of colors - all blended together with no distinction between where peach lets off & orange begins. "As you limit the number of colors available to choose from - say down to 16 - the wheel begins to have definite boarders between colors and the computer speeds up - it functions more efficiently when it doesn't have to sort out displaying all the colors in an image.

Ultimately a monitor can limit the visual field to black & white."The simplest processors function in monochrome. But the reality of the world is technicolor. Black & white is simple, uncomplicated, faster - but not helpful for doing further analysis - not helpful for appreciating deeper meanings in the shades of colors available in reality."

Paula's metaphor suggests that reductive identity categories function as a sort of shorthand which makes defining the self easier, but which never tells the whole story. Critiques of identity-based politics that require unity rather than complexity for activism acknowledge the provisional usefulness of identity categories despite their fictitious reductionism. Moreover, Paula's metaphor suggests that because the same image/person is viewed through more restrictive lenses becomes more and more demarcated by borders, it is the viewer who defines the viewed -in ways that either honor or deny complexity.

Carolyn, in discussing this issue, says:

"Identity is more like a vegetable soup made up of many different ingredients. [She goes on to say, however, that some people] will try to pick out (ingredients or identities) that they don't like [which feels like partial rather than total acceptance]. "Often identities, like ingredients, are not obvious and require some stirring up or delving a little deeper to discover. But visible or invisible, they combine, merge, and tumble to make something that cannot be entirely separated or divided while maintaining the integrity of the whole."

In both metaphors there is an understanding of the ways that how one is viewed or represented by others is often partial and simplistic. It is the inability to see ambiguity and nuance that results in incomplete notions of the self. In claiming identities that are interconnected we seek to speak against reductionist and overly determinist ways of envisioning identity.

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