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Who Goes There and How?:  
Lesbians and Disability

by Chris Taylor

As a queer activist, I've always thought that I've been very aware of injustice and oppression in the world. I've been involved in my community and one of many insisting on the importance of justice for all. I try to always keep in mind how necessary it is to be visible as a lesbian. A little over a year ago when my partner became disabled, I began to learn that I didn't really know anything about invisibility. I learned about an entire population of people that are ignored, left out of most discussions regarding their own lives. I learned that disabled lesbians are not only invalidated and marginalized by the larger society, but are ignored and avoided by able-bodied members of the queer community as well. And, I learned how I've participated in the process of isolation and alienation, and how I might have gone on not seeing had it not been for my partner's disability.

The invisibility of disabled lesbians is clear in the lack of research regarding their experience in society. Finding literature specific to lesbians and disability has been difficult at best. While I have found works written by disabled dykes that speak to the lived experience of being disabled, I have found little academic research that addresses the problems and possible solutions for these women in their negotiation of a heterosexist and ableist society.

In Adrienne Asch and Michelle Fine's 1997 feminist essay "Nurturance, Sexuality and Women With Disabilities," they admit that the research on disabled lesbian's experience "remains to be explored" (247). Susan Wendell writes in her 1997 essay, "Toward a Feminist Theory of Disability" that "feminist perspectives on disability are not yet widely discussed in feminist theory, nor have the insights offered by women writing about disability been integrated into feminist theorizing the body" (261). This is something I did not notice in my own study of feminist theory and it might not have occurred to me at all had my partner not become disabled.

Looking at disability was something so new to me, I didn't know where to begin. "Disability, like feminism, offers new perspectives, sometimes unsettling ways of looking at questions to which we thought we had the answers" (Frank, 26). This was where I was. I'd never really looked at disability before, I think, because I was afraid. And, I thought I knew all the answers, knew everything there was to know about oppression and marginalization.

When I first learned of my partner's disability I wept for days. She is an amputee, right arm and right leg. I couldn't believe that there wasn't some way to undo it. I grieved for the loss of her arm and leg, constantly waking up at night with the shocking realization that nothing would change her loss. They weren't going to grow back. There wasn't going to be any team of scientists to make her into the bionic woman. I feared what this meant for me, what would

happen to us. I knew it wouldn't make any difference in how much I loved her, but I knew it would change how we lived. I knew it would change how we both moved through the world. I expected the stigma of disability to color our lives. "Stigma often results in a special kind of downward mobility" (Coleman, 218). People lose their place in the social order. For lesbians, who have no place in the social order to begin with, this downward mobility can be particularly defeating. Disabled lesbians do not just become "non-persons," they become completely invisible. Goffman wrote of stigma as a kind of branding of people. It's interesting that for lesbians, the brand exists, but society doesn't look at them, it looks through them. At the Optometrist, the doctor does not speak to my partner even though she is right beside me. The Doctor asks me, "Can she get into the chair?" This creates a kind of invalidation that is hurtful and isolating.

Total strangers feel that asking my partner, "What happened to you?" is perfectly acceptable. I suppose it would not be so acceptable if we were asking them how they managed to become such rude adults, but our feelings are discounted. The disability cancels out humanity. I say "our" feelings as it seems that my connection to my partner renders me disabled also. It seems that I am disabled by association. My disability by association insists that I be reflexive regarding my able-bodied life and experience. Like most able-bodied people, I don't think I'd ever considered my privilege before.

"One in six Americans is disabled; no one wants to find out they could be next" (Brownworth, 13). With so many disabled Americans, how is it that we can make such a huge number of people invisible? In the same way that lesbians are invisible, the answer to this question is that we don't want to see them because we don't want to be them. The most

comfortable way for us is to ignore seeing past our privilege as able-bodied is to pretend the disabled do not exist. The first visibly disabled lesbian I met was coming to meetings of an organization I belong to. She was in a wheelchair. I remember being distinctly uncomfortable with her. I didn't go out of my way to make eye contact with her, let alone speak to her.

I didn't think again about how uncomfortable I was around this woman until I visited my partner in the rehabilitation hospital. I saw a lot of people recovering from surgeries, accidents, strokes. They would gather in a garden area of the hospital where they would sit and play cards, smoke, talk about the hospital, their rehab, physical and occupational therapy, and smoke some more. The garden was this place where everyone could come outside and feel like even if they weren't still part of the world, at least they could see the sky.

Gradually, I became more comfortable with the people at the rehabilitation hospital. The discussions in the garden often centered around practical matters of how bad was the food going to be that was served that day; or would the annoying roommate stop whining. When I wasn't visiting the hospital, my partner and I talked on the telephone constantly. She would talk about how much she was looking forward to becoming an interesting person again, rather than one who was so narrowly focused on the hospital world of food and annoying roommates. She talked of learning to be a better self-advocate as it seemed that no one in the hospital was going to step up for patient concerns.

It was interesting to me that those in the hospital did feel that they had become less interesting people in that their focus became so narrowly defined. Food was the biggest issue. Of course, the hospital food was awful. There was a small corner grocery across the street and every time I went to the garden with my partner for a smoke, someone would say, "Hey, are you going

to the store?" I made a lot of trips to that store. I couldn't resist when they asked. Orange soda, ice cream and candy bars made a huge difference to people living on plain Jell-O.

It took me a few trips to New York before I realized the rehab hospital had a culture within it that I'd never experienced before. My partner is from Brooklyn and when she was injured she was self-employed with no health insurance. In New York City, this means you will probably end up in a city hospital, over-filled, under-staffed, and under-funded. I began to call this the "poor people's hospital." Here in the Midwest, we have no concept of what this means. When we get sick here, we usually go to the same hospital as everyone else. We don't end up in Crown Heights or Flatbush begging for a nurse to come in and take away the bed pan that's been sitting full next to us all morning.

Of course race and class affect how one is treated (or not treated) when disabled, when queer, in any oppressed group. Of course, the hospital my partner was in that I called "the poor people's hospital" was mostly African-American, Puerto Rican, and West Indian. As a Jew, my partner felt that her situation at the hospital was further complicated by the fact that other residents wondered why she was there, automatically assuming she was rich because she is a Jew. This antisemitism carried over when dealing with the weekend groups of praying elderly women that showed up to every hospital room to save souls and recruit membership in the many store-front churches of the neighborhood. Many times these women would come into one's room, welcome or not, and begin to pray at the bedside.

On one particular occasion, my partner was lying on her bed, watching television, when one of the praying ladies came in. She asked my partner if she could pray for her. My partner told the woman she was Jewish. The woman asked if she could pray anyway. My partner said, "sure,

why not.” She didn’t think it would hurt to be prayed for.

The woman proceeded to pray for her, “Heal her heathen soul.” On another occasion, one of the nurses asked her what she was listening to on her headphones. My partner told her that she was listening to Gregorian Chants. The Nurse said, “Well, if you weren’t listening to that stuff, you wouldn’t be into the crazy things you’re into.” Of course, this particular nurse had figured out my partner’s orientation.

The hospital experience is particularly frightening for a lesbian. Both my partner and I considered ourselves “out” in our communities prior to her hospitalization. We were activist, involved in the work of creating more lesbian visibility. However, being out in the hospital while at the mercy of several fundamentalist nurses and staff members, is another story. We learned to do many things very well that we’d previously sworn we’d never do. We learned to talk in code. We kept our voices down. We kissed in empty elevators between floors. Our new closet was not a matter we really had to think about much. It was necessary for survival. “What if they find out and decide to stop bathing me?” my partner would laugh. But, we knew that was nothing to joke about. When depending on the staff for everything, exposure as a lesbian could not only be uncomfortable, but dangerous. What if the staff decides to stop bathing you? What if they decide they have to heal you from your torment, or exorcize the demons from your soul? What if a staff member decides that all you need is a good man?

As long as my partner’s exhusband continued to visit, the other residents seemed satisfied. They would joke about the two of them getting back together because this ordeal had made them closer. Even when I was there helping my partner prepare for the move to Kansas, other residents and staff members talked of what a great friend I was that I would invite her to

move to Kansas with me.

In many studies, lesbians report that they avoid health care do to the insensitivity of health care providers or for fear of how such an intimate relationship may be violated by their coming out (Dull and White, 97). What do lesbians do when faced with a medical condition that does not allow them to withdraw from obtaining care, when they are hospitalized? Lesbians are forced to withdraw, deny who they are. They are forced to pretend. For my partner who was used to being out and active in her community, this denial created a kind of stress and alienation that complicated her relationships with staff members and other patients. This denial and isolation results in a kind of post-hospital, post traumatic stress where one constantly forgets that she is now in a safe place, still in fear of what it may mean to be outed.

We relied on our invisibility to keep our secret at the hospital, to keep safe. We knew they wouldn't figure it out because they weren't looking for it. That might have been different if we had been men, but as women (women who are already invisible) we were kept safe from exposure. Other patients and staff seemed more than happy to accept me as the woman who flew to Brooklyn to be with her friend during her rehabilitation. If they wondered about the nature of our relationship, it never showed. They never questioned why "a friend" would spend so much money flying from Kansas to New York so often. We joked about how we are so invisible as women that we could have been having sex on one of the tables in the garden and no one would of noticed except to ask if I would go to the corner store for them.

While I pretended to be the friend visiting and calling often, my partner's exhusband enjoyed an access to information I was not allowed. Heterosexual privilege in action. When I called the hospital for information after learning that my partner had been taken to the emergency

room with an infection, I was told that no information could be given out over the phone. The ex husband was able to call and get the information, then call me and pass it on. He was aware of his privilege as a man, as the “husband.” When we joked about how hard it was to find out anything through the bureaucracy of the hospital, he would talk of how he’d say, “Dammit, I’m her husband,” and find out what we needed to know. I didn’t have that privilege.

Many of the people in the rehabilitation hospital were ready to be released, but waiting for accessible housing. My partner talked a lot about how easy it was to get around in the hospital, wondering how difficult it would be on the “outside.” I thought again of the woman who came to the meetings, how she wasn’t sure if she could come to a movie with us because the theater in which we were seeing the film had stairs. At the time, I remember feeling ashamed that I was somewhat annoyed that we all had to spend so much time figuring that out. “Disability is frequently regarded as a personal or family problem rather than a matter for social responsibility” (Wendell, 265). I didn’t think about how something as simple as access to a building could be so huge. I didn’t think about having to make decisions every day about where one could or couldn’t go based on whether or not one could get into the building. And I didn’t think at all about my role in denying access. In a 1976 manifesto entitled “Fundamental Principles” the Union of the Physically Impaired Against Segregation stated: “In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society” (Barnes, 28).

Everywhere that my partner and I go now is determined by access. When invited out for dinner with friends, we have to first ask, “Is it accessible?” It’s difficult to visit small cafes or

shops together. When dining out, we frequently have to resort to chains because we know the big corporately owned restaurants such as On The Border or Chilli's will be at least moderately accessible. Even then, there will be problems in these restaurants during busy times. Sometimes I feel anger that it's so very hard to just get around. And, a lot of the time, I feel shame in that I never really thought about it before. Accessibility did not touch me before now and I feel that it is criminal, and shameful that we live in a world that isolates by denying access.

When we deny access, we force an isolation upon people that we don't even think about. We don't think about the implications of our alienation because we don't see it:

Not surprisingly, friends- the ones I had thrown parties for, gone to movies and dinner and dancing with, traveled with, led marches with- all began to disappear out of my now-disabled life. For some reason they couldn't understand that if their houses or the restaurants we used to go to or the movie theaters or the bookstores weren't accessible to me in my wheelchair, I couldn't go there. (Brownworth, 13)

Isolation seems to go along with disability in American society. If we announced to the public that a certain population of people were being denied access to theaters and restaurants, there would be outrage. Yet, this is happening to disabled people every day and it rarely makes the national news as the civil rights issue it is.

In sociology, when we study deviant behavior, the disabled are often included as different from the norm:

There are various ways of using the word normal. In theory it could be a value-free word to mean merely that which is common, and to be different from normal would not therefore necessarily provoke prejudice. In practice, of course, there are very strong

values tied up with what our society considers to be normal and abnormal. The idea of normality is inherently tied up with ideas about what is right, what is desirable and what belongs. (Morris, 16)

When we discuss what's "abnormal" in sociology, it's supposed to be value-free, but rarely is. By cataloging disability (and lesbianism) as deviant, we as sociologists, participate in labeling theory, the very theory we study. It's often a frustrating discussion, one of an endless chicken and egg dialogue. When my partner and I go to the grocery store together, there are varying reactions to her disability depending on whether or not she is wearing prosthetic limbs. With the limbs, she passes, even while in a wheelchair. Without the limbs, the stares are lingering questions that ask what are we doing out in public if we cannot be "normal." With prosthetics, my partner can be the heroine, what we jokingly call the "Tiny Tim Cripple." Without prosthetics, no one wants to see her. The staring lingers and yet, at the same time, people look right through her.

I thought, as a lesbian, that I had experience in being invisible. However, when disability is added into the equation, it changes everything. Thus, when I am with my partner, I am just as invisible as she is until I demand that my voice be heard. A few months ago, we were in the campus bookstore at the counter for scholarships, picking up my partner's books. I was leaning on the counter and she was beside me in the wheelchair. A man stood directly behind me. I watched the clerk come up to within a foot or two of me, look right through me, and ask the man behind me if she could help him. I sputtered out, "That was extremely rude." She continued to look through me while the man behind me apologized and stepped into another line. I had never been so blatantly ignored and it felt strange, but mostly it just felt hurtful. And, I knew it was because the clerk didn't want to acknowledge us, because by doing so, she somehow might of

acknowledged our difference. That could mean guilt by association.

Being looked over is hard, frustrating. The isolation of being denied access is a factor that further compounds invisibility when one is a lesbian. Disabled lesbians are denied civil rights three-fold. First, for being women, for being queer, and again for having the misfortune of not being able bodied. On top of dealing with the everyday decisions on where it may or may not be safe to come out, one has to also consider whether or not there will be access to those places. When one adds race and class into the mix, it's easy to see how far removed from what American society considers acceptable one can be:

Lesbians with disabilities do not find community easily. If we live with personal assistance and assistive technology, our lives become more complicated. Is the dyke dance wheelchair accessible? Will I have the personal assistance I need to attend the support group? Whose home besides my own is welcoming to wheels? What dykes, if any, have worked through their own ableism and can relate to a cripple without shame, fear or disgust? And what happens if my clunker of a wheelchair poops out on my date? Or, more likely, who in this community of amazons and fitness freaks will find the beauty that exists in my fat, disabled body?" (Platt, 183-184).

Even when there is access, that doesn't mean that one will be included.

My partner and I decide daily when dealing with various health and welfare agencies whether or not it's safe to tell them that we are partners. Often, when we come out to doctors and other professionals, we find ourselves doing it over and over again simply because they don't hear us. At a support group I was introduced as the partner. Even after coming out, with her arm

around my shoulder, a male member of the group asked us later if we were sisters. It's easier for people to see me as a caring friend than as a lover. After all, the disabled don't have relationships. They certainly don't have sex, so why would my partner need to come out as a lesbian?

American cultural stereotypes dictate that being a lesbian is all about sex, while the disabled are deemed non-sexual in our society and women's sexuality is not taken seriously under patriarchy. The first thing people see is not my partner and I as a couple, but my partner's disability. That disability precludes any conclusions they might make about our relationship. It cancels it out. "Asexual objectification" is the assumption that sexuality is inappropriate in disabled people (Thomson, 285). It's a complex juxtaposition. On the one hand, lesbians have been fighting to prove that they are about more than sex. On the other hand, disabled women are fighting for recognition of their sexuality.

Asch and Fine write that our culture sees "being female and disabled as redundant, whereas being male and disabled is a contradiction" (249). As my partner and I negotiate how we both move through the world differently now, I see how my own assumptions about disability were as difficult to overcome as my hard-wired heterosexuality was. When I accepted my own lesbianism, I saw myself as tuned into the issues of social justice, of equality. However, I now see how easy it was to overlook a huge population of people, a population of which most of us, at some point in our lives, will become a member.

The big question is, where do we go from here? As lesbians fight for equal justice, how do we learn inclusion? How do we learn the importance of seeing our disabled sisters, not seeing through them? For me, it was learning that my fear of disabled people was unfounded, and that

the way I looked through them is the way homophobes and patriarchs look through me. It permeates our culture. Patriarchy hard-wires it into us from the time we're born.

There is not a "them" out there doing this. It's us, all of us. Once we acknowledge our place, we're on our way to seeing, to seeing everyone. It isn't easy and it makes us uncomfortable. That discomfort is similar to the discomfort I felt prior to coming out. I got over that. We can get over it. Lesbians are not immune to the fear created by stereotypes. We fear disability the same way heterosexuals do. "Ability isn't permanent, it can be taken away" (Weinberg, 251). We fear it will happen to us and we turn away. In all likelihood, it will happen to us and I'd prefer not to be left out when it does. I'm still learning and something a friend of my partner's said when she first became disabled keeps running through my head. "You may not be queer; you may not be black; but you will be disabled. At some point in our lives, we all will be."

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