

Disabled Women's Lives

By Alessandra Iantaffi

Researching disability as an ally, and not a stranger, involves a personal involvement on my part, a questioning of my own asthmatic, fibromyalgic, but by my own definition, non-disabled self. It also involves an exchange of stories.

Disability issues, like feminist issues, stem from common roots of prejudice, discrimination and oppression, where the personal becomes political and, when talking to disabled women, the borders and divisions start to blur around the shape of a complex identity.

Most research on disability have been carried out by non-disabled researchers acting as experts, trying to promote measures they think are best for people with disabilities or 'special needs.'

Not wanting to reinforce this status quo, I try to avoid complacency in my own research praxis. I challenge my own attitudes and try not to misconstrue others or be misconstrued myself.

When I began researching the lives of women students with disabilities in October 1995, I was nervous because although I have disabled friends, they are mostly deaf. I have had little contact with other people with disabilities.

One of my big worries was meeting those who were wheelchair users since I was not too sure about how to deal with the 'helping' issue. I was, however reassured, and briefly embarrassed, when one participant, with whom I had laughingly shared this concern, advised me not to be

preoccupied with wheelchairs as they "do not talk back."

As a feminist and a woman who likes to think of herself as fair and opposed to oppression and marginalisation, I wanted to be different from researchers who saw themselves as experts and people with disabilities as "other."

Yet, I had a chip on my shoulder: I was scared of asking the wrong questions, of offending sensibilities and encountering hostility. Until I realised that the feelings I had were the same ones expressed by others toward feminists. It is easy to slip into a vicious circle of division and suspicion.

We, non-disabled feminists, often tiptoe around each other, and especially around disabled women, because they supposedly have a double disadvantage. By doing so we ignore them, or represent them as an oppressed minority, a special case that does not touch us. Theirs is a scenario of tragedy, pain, loss and disadvantage; we project onto them our own fears of pain, dependence and mortality.

In the name of common womanhood, I embarked on a dialogue of discovery and tried to uncover the lost tales of disabled women stu-

"If you keep saying me and them, you subscribe to that division between 'us, academics, able people on our side of the world,' and 'them, disabled, unable, different' I think you can say us. You should say us. You are not that different really."

dents in higher education in England. I wanted to highlight not just their struggle, but their survival.

I began a series of in-depth interviews with a group of 15 volunteers and a brief correspondence with 10 others whom I was unable to meet personally.

The women varied in age, abilities, class, nationalities, educational background and type of disabilities. All of them were white; I was unable to get data on black disabled women in higher education.

The Struggle is the Same

The experience of talking to members of the group gave me a strong sense of identification with their experiences as women students. It reinforced the concept put forward by Jenny Morris in her book, *Encounters with Strangers: Feminism and Disability*, that the women's movement and the disability rights movement have much in common. This view was shared by one of my interviewees. I had sent the interviewees prior information about myself in which I had included an explanation for my reluctance to say "us,"

and the reasons for referring to women with disabilities as "them." She counseled me: "If you keep saying me and them, you subscribe to that division between 'us, academics, able people on our side of the world,' and 'them, disabled, unable, different' I think you can say us. You should say us. You are not that different really."

The more experiences I listened to, the more I agreed with her. However, up to now I have not been able to say us, at least not in all contexts.

Like other women in the traditionally male-dominated academia, the interviewees, with varying degrees of emphasis, talked about some aspects of their experiences in what I refer to as "warfare language." They talked, not just of struggling and fighting within the academic context, but also of the strategies which they have had to use to cope with various barriers to access and/or with people's attitude toward their disability. They have had to struggle, in their own words, "to win against the odds."

"Having to prove myself all the time is tiring..you are always fighting to prove you can do it," one interviewee says. Adds another: It's a matter of survival really. You have to do what's best for you."

To make it and in order to be listened to, they have had to adopt different kinds of attitude such as being "determined and forceful, demanding, confident and assertive, and harsh."

They all expressed discomfort about such attitudes and felt that they were "forced" or "pushed" into it, especially since none of them wanted to be seen as "difficult." Being "difficult"

is indeed, often seen as not a “nice, desirable quality” in a woman.

An interviewee was distressed about her anger at her institution’s inability to understand her needs, and went for counseling to deal with it. “I’m seeing a counselor, not just because of all this, but all the problems kind of piled on top of each other,” she said. “I was talking to her about how angry I felt, and she was just saying that it didn’t show. I’m very articulate but I’m very good at not being angry. And she was just saying, ‘This isn’t good for you. How about letting it out, showing your temper?’ I was like, I don’t think I’ll do that, this is not the way we behave...”

Many of these disabled women have also not been expected to pursue higher education and felt a constant pressure to having to prove “them” (parents, educational psychologists and/or teachers) wrong.

All took their education seriously but found most people’s reactions toward them patronising. “I would actually like a career. The assumption has been that I am doing this to amuse myself,” one interviewee said. “The assumption is that I am just a disabled person who is filling in her time, because (I) have got nothing else to do. When people, at home, ask me about my work they say: ‘Oh it keeps you busy!’ And I say, no it doesn’t keep me busy; it is my work...Does your work keep you busy?”

Another interviewee laments that “like other women, disabled women in academia are often not taken seriously, unless they prove themselves worthy in other people’s eyes. They are oppressed as disabled individuals and as women.”

Feminism can and should include the experiences of disabled women if it wants to strive for authenticity. Similarly, disability studies must include disabled women.

Dialogues can be painful but rewarding, and, in this context, necessary if we want to expand our horizons and move towards a more inclusive definition of womanhood. Women with disabilities are not the first to challenge the boundaries of feminism, other dialogues have preceded, and others will follow, so that as women we can meet and gain from our strength. One of these dialogues—between feminism and Black women—seems to resemble the current tentative encounters between women with disabilities and non-disabled feminists. From this dialogue I will borrow an unpublished poem by Audre Lorde, whose message resonates the thoughts conveyed by my interviews:

*We have chosen each other
and the edge of each others battles
the war is the same
if we lose
someday women’s blood will congeal
upon a dead planet
if we win
there is no telling
we seek beyond history
for a new and more possible meeting. ♪*

Alessandra Iantaffi is currently a researcher at the University of Reading (UK) where she completed her PhD on the experiences of women students with disabilities in Higher Education in 1999. She is Italian but moved to the UK in 1993. Her research interests range from Women’s Studies to Disability Studies. She also has a secret passion for linguistics and the European Union.