

Must Disability Always Be Visible?

The Meaning of Disability for Women

by Sharon Dale Stone

Pour une femme, aujourd'hui, qu'est-ce que cela représente de s'identifier comme femme handicapée? C'est ce que l'auteure examine en abordant les questions suivantes: la dichotomie traditionnelle corps/esprit; la normalisation de la souffrance; comment les femmes sont socialisées à percevoir leur corps; et, le refus de croire qu'un très grand nombre de personnes présentent un handicap.



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I once complained to my mother about how different I felt on account of my (largely invisible) disabilities, and she pointed out to me that practically everyone has something wrong with them. As a case in point, she drew attention to the large number of people suffering from poor eyesight. That silenced me for a while, but lately I have begun to ponder what it means to identify as disabled. If disability is so widespread that it is the individual with the perfectly functioning body who is truly remarkable, then why is it that we speak of people with disabilities as though they constitute a minority?

For some time now I have been grappling with the question of what it means for a woman to identify as disabled; I still find that the questions are more numerous and come more easily than the answers. I don't pretend to have definitive answers to the question of what disability means for women, but I do think that the following ideas suggest a way into the problem and bear serious consideration.

References to physical or mental disabilities call attention to the body. This is because no matter how diligently our culture¹ works to convince us that mind and body are separate, they are not separate. Indeed, the intimate relationship between mind and body was explicitly recognized in the nineteenth century as compulsory schooling for children was being promoted (Prentice, 29-30). At the time, the school promoters argued that one must train the body in order to train the mind. It is for this reason that physical education was introduced into the curriculum and has remained there to this day. In the nineteenth century, these men did not argue that the mind and body were of equal value; they were quite adamant that the body was inferior. Moreover, their recognition of the intimate relationship between mind and body

was used primarily to justify the assumption that someone with a feeble body must therefore have a feeble mind. Contemporary culture has retained this noxious assumption, yet seems to have forgotten the premise upon which it was once based: that mind and body are not separate.

When thinking about disability, it is useful to notice that in our culture, notwithstanding the fleeting recognition of mind/body unity

that appears every now and then, the theoretical separation of mind and body is very old. Equally old is the idea that the mind is more valuable than the body. Today these ideas are increasingly being questioned, yet our culture continues to assume that mind and body may be regarded as separate and unequal. As Lois McNay says:

This [mind/body] dualism privileges an abstract, prediscursive subject at the center of thought and, accordingly, derogates the body as the site of all that is understood to be opposed to the spirit and rational thought, such as the emotions, passions, needs (126).

Thus, our culture encourages us to "rise above" and transcend the body, to pretend that it does not really exist. Much of this, of course, is at bottom tied to a fear of death, and can be seen as an attempt to deny the inevitability of death. Nevertheless, we are not encouraged by our culture to pay attention to whatever aches and pains we may suffer. Rather, we are encouraged to ignore them and go about our business as though our bodies had nothing to teach us. Indeed, it is because our culture holds the body in such contempt that we are able to find ourselves living in a world that is structured, as Susan Wendell has pointed out, "as though everyone can work and play at a pace that is not compatible with any kind of illness or pain" (111). Those who are best at denying the limitations of the body reap monetary rewards (e.g., the workaholic executive, the supermom, the sports athlete), while those who either refuse to ignore or are unable to ignore their bodily limitations reap no rewards from our culture.

Our culture does not pretend that no one ever suffers. Everyone

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is allowed, on occasion, to have a headache, an upset stomach, or the common cold. But no one is allowed to let such ailments interfere with daily tasks. Our culture admires those hardworking individuals who, despite sniffles, bleary eyes and a temperature of 101 degrees Fahrenheit, go to work and get things done. Similarly, our culture admires the individual who has, for example, a persistent pain somewhere in the body yet refuses to go to a doctor. Such individuals, our culture implicitly asserts, are to be valued for an ability to rise above the body and indeed, ignore it. Our culture teaches us that "a pain in the neck" may be felt physically as well as recognized metaphorically, but "a pain in the neck" ought to be regarded as a minor inconvenience to be overcome, not something that puts a stop to the achievement of goals.

In this manner, disability becomes unspeakable. Those who dare to call attention to their bodily "imperfections" are shunned. Their demonstrated inability or refusal to "rise above" the body is taken as evidence of their inferiority, and they are not taken seriously. Those who cannot conceal their disabilities are encouraged to remain out of sight—whether in an institution or in a private home matters not, so long as the general population does not have to deal with their presence.

Those who can conceal their disabilities, however, are welcome to mingle with the general population, but only to the extent that they are successful in concealing their disabilities. Thus, the old woman with arthritis is allowed on the street, but she is assumed, because of her advanced age and the difficulty she may have with walking, to be incompetent. She can be easily dismissed because of her inability/refusal to conceal her bodily "imperfections." Her age alone is enough to make her "other" (Posner) and so, whatever disabilities she might have acquired in the process of living may also be con-

sidered "other." To the extent that young women take notice of her, they may comfort themselves that arthritis is a disease of the old, and this thought prevents them from identifying with the old woman.

Arthritis, however, is not a disease exclusive to the old, and is often present in the bodies of children. What happens when it is a young woman who has arthritis? If a young woman complains of not being able to walk far because of arthritis, she too is looked down upon. No one can use her age to dismiss her, but she is looked down upon because she is seen to be giving in to the infirmities of the body. She is regarded as inferior in her inability to withstand pain. She may be told that she must keep moving, for it is only with continual movement that the joints may stay oiled and supple, she may be told by someone else that she is not exercising properly, and she may be told by still another person that if she pays too much attention to her body, she'll never get anything done.

In this manner, the young woman with arthritis is encouraged to "normalize" her suffering (Abberley, 17). She is asked to participate in maintaining the huge silence surrounding the existence of disabilities in young bodies. Suffering is part of the human condition, she may be told philosophically, and so there is nothing unusual about her pain. From this perspective, she has no cause for drawing attention to her "imperfect" body. She should get on with life, grin and bear it. Above all, she is not encouraged to identify herself as disabled.

In our culture, disability is equated with incompetence and inferiority. The woman (or, for that matter, the man) who says she is disabled is understood to be announcing her own incompetence and inferiority. It is on this basis that well-meaning friends may counter her announcement of disability with the statement, "But I don't think of you as disabled." Intended as a

compliment, the statement is meant as an affirmation of her ability to participate in social life. Sometimes, the statement is uttered in an attempt to deny that the woman who says she has disabilities has any limitations beyond those that are considered normal, and thus the statement is meant to deny her ability to define her own reality. At other times, the statement is uttered as an affirmation of the essential incompetence and inferiority of disabled people.

The body is not something with which women are trained to feel comfortable. In our culture, women learn that their value resides in the attractiveness of their bodies. It is small wonder, then, that even women who are conventionally attractive are continually alert to the slightest of bodily "imperfections." And it is small wonder that we have a huge cosmetics industry that caters to women who are terrified of drawing attention to the imperfections which they perceive in their bodies. In our culture, women learn at an early age that it is incumbent upon them to do their utmost to conceal their "imperfections." Women learn that there is nothing about an "imperfect" body to celebrate, such a body is cause for shame.

Perhaps the lengths to which women in our culture will go to deny the widespread existence of disabilities can be illustrated with the following anecdote.

Several years ago, I read an article about a lesbian organization in which I used to be active. Written by Becki Ross, the article was based on interviews with a number of lesbians who had been involved in the organization. Of everything that was said in the article, one particular line has stuck in my mind. That is, Ross discussed the kinds of women who used to attend events there, and stated that: "No one that I interviewed remembers ever seeing a disabled lesbian" there (Ross, 81). Had I been interviewed, Ross would not have been able to write that line, but

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what is more interesting to me is that I was not the only lesbian there who was disabled.

I note that in the article Ross did not conclude that there were no disabled lesbians there, only that her informants do not remember any. This gives me pause for thought, and prompts me to wonder exactly what counts as being disabled. I wonder if one must sit in a wheelchair in order to be recognized as disabled, or at least use crutches for walking. If these highly visible pieces of equipment are required in order to be recognized as disabled, then it is not surprising that no one remembers seeing lesbians with disabilities at that organization, because meetings and social events were held in a very inaccessible building. But as anyone with any knowledge about disabilities knows, there are all kinds of disabilities and many of them are not obvious. It would have been more correct for Ross's informants to have stated that they did not see any lesbians with disabilities that were so visible they could not be hidden.

Although I have been disabled since childhood, either my disabilities are not usually apparent or else others assume that any clumsiness on my part or any disinclination to do certain things can be ascribed to some amorphous strangeness. For a very long time, I was not inclined to enlighten others about my disabilities and in fact, worked hard at trying to forget that they are part of who I am. Certainly, I was not interested in identifying as disabled during the period that Ross wrote about in her article, and I have written about this elsewhere (Stone).

Yet, I have to wonder why the lesbians who Ross interviewed assumed that disabilities are always visible, or at least that if they had seen a disabled lesbian, they would have recognized her as such.

Off the top of my head, I can think of two other lesbians with invisible disabilities who were often present at that organi-

zation's meetings and/or events. One had diabetes and another was mobility impaired. These two were lesbians that I personally knew about, and I did not know about them because they went around announcing their disabilities to one and all. Regarding the lesbian with diabetes, I only knew about her because I heard her speak at a meeting for women with diabetes which I had attended with my lover who was diabetic and by then, blind as well (my lover had also been to the lesbian organization in question, but was not actively involved). Regarding the lesbian who was mobility impaired, I knew about her because she told me one evening when the two of us were trading personal stories that we did not usually talk about. Then, there was also the lesbian who was epileptic and had a seizure in front of a group of us. My point is that I am sure that there were all kinds of lesbians who had disabilities that were not usually apparent and which, like me and others I knew about, they did not talk about.

This is not intended to blame those who don't remember seeing any disabled lesbians for their lack of awareness, and it is not to blame those of us who did not speak up about our disabilities. All of us were doing nothing more than conforming to and reinforcing the cultural myths about disability with which we were familiar. By not noticing or denying the presence of lesbians with disabilities, we were doing what women in our culture are supposed to do (deny the existence of bodily "imperfections").

We did not challenge the theoretical separation of mind and body, and we did not challenge the belief that disability must always be immediately visible. That we were unable to break out and challenge cultural myths about disability is testament to the strength of those myths. Ultimately, this points to one more area where feminists need to do a lot of work.

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¹Where the essay refers to "our culture," this should be read as shorthand for the dominant culture of late twentieth century North America.

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