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Author: King, Ynestra

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Abstract

This article describes the experiences of a woman with a physical disability and how this affects her own identity and influences the way people perceive her. How people react towards her and attempt to mask their feelings is covered in detail. She also explores the tendency people have to lump everyone with any kind of disability together, sometimes with terrible consequences. **Keyword:**
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The Other Body

Reflections on difference, disability, and identity politics

BY YNESTRA KING

Disabled people rarely appear in popular culture. When they do, their disability must be a continuous preoccupation overshadowing all other areas of their character. Disabled people are disabled. That is what they "do." That is what they "are".

My own experience with a mobility impairment that is only minorly disfiguring is that one must either be a creature of the disability, or have transcended it entirely. For me, like most disabled people (and this of course depends on relative severity), neither extreme is true. It is an organic, literally embodied fact that will not change— like being a woman. While it may be possible to "do gender", one does not "do disability." But there is an organic base to both conditions that extends far into culture, and the meaning that "nature" has. Unlike being a woman, being disabled is not a socially constructed condition. It is a tragedy of nature, of a kind that will always exist. The very condition of disability provides a vantage point of a certain lived experience in the body, a lifetime of opportunity for the observation of reaction to bodily deviance, a testing ground for reactions to persons who are readily perceived as having something wrong or being different. It is fascinating, maddening, and disorienting. It defies categories of "sickness" and "health", "broken" and "whole." It is in between.

Meeting people has an overlay: I know what they notice first is that I am different. And there is the experience of the difference in another person's reaction who meets me sitting down (when the disability is not apparent), and standing up and

walking (when the infirmity is obvious). It is especially noticeable when another individual is flirting and flattering, and has an abrupt change in affect when I stand up. I always make sure that I walk around in front of someone before I accept a date, just to save face for both of us. Once the other person perceives the disability, the switch on the sexual circuit breaker often pops off - the connection is broken. "Chemistry" is over. I have a lifetime of such experiences, and so does every other disabled woman I know.

White middle-class people - especially white men - in the so-called First World have the most negative reactions. And I always recognize studied politeness, the attempt to pretend that there's nothing to notice (this is the liberal response - Oh, you're black? I hadn't noticed). Then there's the do-gooder response, where the person falls all over her/himself, insisting on doing everything for you; later they hate you; it's a form of objectification. It conveys to you that that is all they see, rather like a man who can't quit talking with a woman about sex.

In the era of identity politics in feminism, disability has not only been an added cross to bear, but an added "identity" to take on - with politically correct positions, presumed instant alliances, caucuses to join, and closets to come out of. For example, I was once dragged across a room to meet someone. My friend, a very politically correct lesbian feminist, said, "She's disabled, too. I thought you'd like to meet her." Rather than argue - what would I say? "I'm not interested in other disabled people," or "This is my night off"? (The truth in that moment was like the truth of this experience in every other moment,

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complicated and difficult to explain) - I went along to find myself standing before someone strapped in a wheelchair she propels by blowing into a tube with a respirator permanently fastened to the back of the chair. To suggest that our relative

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experience of disability is something we could casually compare (as other people stand by!) demonstrates the crudity of perception about the complex nature of bodily experience.

My infirmity is partial leg paralysis. I can walk anywhere, climb stairs, drive a car, ride a horse, swim, hang glide, fly a plane, hike in the wilderness, go to jail for my political convictions, travel alone, and operate heavy equipment. I can earn a living, shop, cook, eat as I please, dress myself, wash and iron my own clothes, clean my house. The woman in that wheelchair can do none of these fundamental things, much less the more exotic ones. On a more basic human level I can spontaneously get my clothes off if I decide to make love. Once in bed my lover and I can forget my disability. None of this is true of the woman in the wheelchair. There is no bodily human activity that does not have to be specially negotiated, none in which she is not absolutely "different." It would take a very long time, and a highly nuanced conversation, for us to be able to share experiences as if they were common. The experience of disability for the two of us was more different than my experience is from the daily experience of people who are not considered disabled. So much for disability solidarity.

With disability, one is somewhere on a continuum between total bodily dysfunction - or death - and complete physical wholeness. In some way, this probably applies to every living person. So when is it that we call a person "disabled"? When do they become "other"? There are "minor" disabilities that are nonetheless significant

for a person's life. Colour blindness is one example. But in our culture, colour blindness is considered an inconvenience rather than a disability.

The ostracization, marginalisation, and distorted response to disability are not simply issues of prejudice and denial of civil rights. They reflect attitudes toward bodily life, an unease in the human skin, an inability to cope with contingency, ambiguity, flux, finitude, and death.

Visibly disabled people (like women) in this culture are the scapegoats for resentments of the limitations of organic life. I had polio when I was seven, finishing second grade. I had excelled in everything, and rarely missed school. I had one bad conduct notation - for stomping on the boys' blocks when they wouldn't let me play with them. Although I had leg braces and crutches when I was ready to start school the next year, I wanted desperately to go back and resume as much of the same life as I could. What I was not prepared for was the response of the school system. They insisted that I was now "handicapped" and should go into what they called "special education." This was a program aimed primarily at multiply disabled children, virtually all of whom were mentally retarded as well as physically disabled. It was in a separate wing of another school, and the children were completely segregated from the "normal" children in every aspect of the school day, including lunch and recreational activities. I was fortunate enough to have educated, articulate parents and an especially aggressive mother; she went to the school board and waged a tireless campaign to allow me to come back to my old school on a trial basis—the understanding being that the school could send me to special education if things "didn't work out" in the regular classroom.

And so began my career as an "exceptional" disabled person, not like the *other* "others." And I was glad. I didn't want to be associated with those others either. Apart from the objective limitations

caused by the polio, the transformation in identity—the difference in worldly reception—was terrifying and embarrassing, and it went far beyond the necessary considerations my limitations required.

My experience as "other" is much greater and more painful as a disabled person than as a woman. Maybe the most telling dimension of this knowledge is my observation of the reactions of others over the years, of how deeply afraid people are of being outside the normative appearance (which is getting narrower as capitalism exaggerates patriarchy). It is no longer enough to be thin; one must have ubiquitous muscle definition, nothing loose, flabby, or ill defined, no fuzzy boundaries. And of course, there's the importance of control. Control over aging, bodily

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processes, weight, fertility, muscle tone, skin quality, and movement. Disabled women, regardless of how thin, are without full bodily control.

I see disabled women fight these normative standards in different ways, but never get free of negotiating and renegotiating them. I did it by constructing my life around other values and, to the extent possible, developing erotic attachments to people who had similar values, and for whom my compensations were more than adequate. But at one point, after two disastrous but steamy liaisons with a champion athlete and a dancer (during which my friends pointed out the obvious unkind truth and predicted painful endings), I discovered the worlds I had tried to protect myself from: the disastrous attraction to "others" to complete oneself. I have seen disabled women endure unspeakably horrible relationships because they were so flattered to have such a conventionally attractive individual in tow.

And then there's the weight issue. I got fat by refusing to pay attention to my body. Now that I'm slimming down again, my old vanities and insecurities are surfacing. The battle of dieting can be especially fraught for disabled women. It is more difficult because exercising is more difficult, as is traveling around to get the proper foods, and then preparing them. But the underlying rage at the system that makes you feel as if you *are* your body (female, infirm) and that everything else is window dressing - this also undermines the requisite discipline. A tempting response is to resort to an ideal of self as bodiless essence in which the body is completely incidental, and irrelevant.

The wish that the body should be irrelevant has been one of my most fervent lifelong wishes. The knowledge that it isn't is my most intense lifelong experience.

I have seen other disabled women wear intentionally provocative clothes, like the woman in a wheelchair on my bus route to work. She can barely move. She has a pretty face, and tiny legs she could not possibly walk on. Yet she wears black lace stockings and spike high heels. The other bus occupants smile condescendingly, or pretend not to notice, or whisper in appalled disbelief that this woman could represent herself as having a sexual self. That she could "flaunt" her sexual being violates the code of acceptable appearance for a disabled woman. This woman's apparel is no more far out than that of many other women on our bus—but she refuses to fold up and be a good little asexual handicapped person.

The well-intentioned liberal new campaigns around "hire the handicapped" are oppressive in related ways. The Other does not only have to demonstrate her competence on insider terms; she must be better, by way of apologizing for being different and rewarding the insiders for letting her in. And the happy handicapped person, who has had faith placed in her/him, must vindicate "the race" because the politics of tokenism assumes that there

are in fact other qualifications than doing the job.

This is especially prejudicial in a recession, where there are few social services, where it is "every man for himself." Disabled people inevitably have greater expenses, since assistance must often be paid for privately. In the U.S., public construction of the disabled body is that one either is fully disabled and dysfunctional/unemployable (and therefore eligible for public welfare) or totally on one's own. There is no in-between—the possibility of a little assistance, or exceptions in certain areas. Disabled people on public assistance cannot work or they will lose their benefits. (In the U.S. ideology that shapes public attitudes and public policy, one is either fully dependent or fully autonomous.) But the reality of human and organic life is that everyone is different in some way; there is no such thing as a totally autonomous individual. Yet the mythology of autonomy perpetuates in terrible ways the oppression of the disabled. It also perpetuates misogyny—and the destruction of the planet.

It may be that this clear lack of autonomy - this reminder of mortal finitude and contingency and embeddedness of nature and the body—is at the root of the hatred of the disabled. On the continuum of autonomy and dependence, disabled people need help. To need help is to feel humiliated, to have failed. I think this "help" issue must be even harder for men than women. But any disabled person is always negotiating both the provisionality of autonomy and the rigidity of physical norms.

From the vantage point of disability, there are some objective and desirable aspects of autonomy. But they have to do with independence. The preferred protocol is that the attendant or friend perform the task that the disabled person needs done in the way the disabled person *asks it to be done*. Assistance from friends and family is a negotiated process, and often maddening. For that reason most disabled people prefer

to live in situations where they can do all the basic functions themselves, with whatever special equipment or built-ins are required.

It's a dreadful business, this needing help. And it's more dreadful in the U.S. than in any place in the world, because our heroes are dynamic overcomers of adversity, and there is an inevitable cultural contempt for weakness.

Autonomy is on a continuum toward dependency and death. And the idea that dependency could come at any time, that one could die at any time, or be dismembered or disfigured, and still have to live (maybe even *want to live*) is unbearable in a context that understands and values autonomy in the way we moderns do.

I don't want to depict this experience of unbearability as strictly cultural. The compromising of the human body before its natural time is tragic. It forces terrible hardship on the individual to whom it occurs. But the added overlay of oppression on the disabled is intimately related to the fear of death, and the acknowledgment of our embeddedness in organic nature. We are finite, contingent, dependent creatures by our very nature; we will all eventually die. We will all experience compromises to our physical integrity. The aspiration to human wholeness is an oppressive idealism. Socially, it is deeply infantilizing.

It promotes a simplistic view of the human person, a static notion of human life that prevents the maturity and social wisdom that might allow human beings to more fully apprehend the human condition. It marginalizes the "different," those perceived as hopelessly wedded to organic existence—women and the disabled. The New Age "human potential movement"—in the name of maximizing human growth—is one of the worst offenders in obscuring the kind of human growth I am suggesting.

I too believe that the potential for human growth and creativity is infinite—but it is not groundless. The common ground for the person—the human body—is a place of shifting sand that can fail us at any time. It can change shape and properties without warning; this is an essential truth of embodied existence.

Of all the ways of becoming "other" in our society, disability is the only one that can happen to anyone, in an instant, transforming that person's life and identity forever. ■

Ynestra King's books include "Ecofeminism and the Reenchantment of Nature", forthcoming this year from Beacon Press. She is the mother of a one-year-old son, Micah.