Editor's note: The following was first published as a letter to the editor in *The Mouth* and is reprinted here by permission of the holder of the copyright. The author has made some changes in the text.

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Disability and Love

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Historians, in general, are taught to ignore "what if" questions. There's a very good reason for this. How can we say what would have happened if, for example, Hitler had won World War II or Napoleon defeated his enemies at Waterloo or America's social policy towards people with disabilities was as enlightened as Scandinavia's has been? We can't, because none of those things has ever happened.

In the last few months when I've read my copies of NEW MOBILITY, THE MOUTH and THE RAGGED EDGE, I've been thinking about such things. The MOUTH came out with another great issue. No surprise. They've been doing that for a lot of years now. I found two articles in particular led filled me with questions.

One came from Josie Byzek, who questioned our movement's motivation. She wondered if we are motivated from anger. I recall with great fondness listening to the great Ed Roberts talk about how anger was a positive emotion. Not because it was an end in itself, but because it motivated people to work for change. I had the wonderful opportunity to know Ed later in his life, when much of his work had already been done, when he'd been married and divorced, when his son Lee was the proudest accomplishment of his life, and when people waited in long lines for chances to speak with him. Ed's great motivator was not anger, though they were plenty of times I saw him angry. No, his great motivator was love. He loved everyone he met. I don't mean he liked everyone; I don't think he did. But he was in love with humanity. He always wanted to meet new people and to know your story.

I talk about Ed and love with fondness and respect and because Josie chose to focus on anger. I also talk about Ed because of the other article. It's a story about how the Supreme Court is taking away our rights and beheading the ADA. I've certainly shared my own criticisms of the ADA and its implementation. I've also run through a gamut of emotions as our rights have been gutted. But to me this article asks the crucial question that none of us seem to want to answer: what is a disability?

What makes someone who uses a wheelchair disabled and someone who wears glasses not? What makes someone who has a brain injury disabled and someone who is eccentric not? In short, how have we come to our definitions of disability?

We, in this movement, are, I believe as guilty as the medical profession we so often criticize for definitions of disability. We've decided that disability has to do with major life activities and we've defined them physically: walking, seeing, hearing; cognitively or mentally: psychiatric disabilities, learning disabilities, retardation; and socially: transportation, working, living alone. No wonder everyone's confused! Aren't you?

I happen to use a wheelchair, have chronic pain, chronic fatigue, and bones that break easily. My condition first appeared when I was six. That certainly makes me a bonafide disabled person for many years now. And yet, I also have a Ph.D.; have made money from working outside the home since I was twelve years old, been married twice, raised a daughter, lived on my own since I was seventeen, written a number of books, been given awards for my poetry, and hope one day (please make it soon!) to make money from my writing. If someone had never seen me they would assume from the previous sentence that I was not disabled. And yet, to get into my dwelling I need all steps removed (or a ramp installed) and to leave my residence I have to get into a vehicle that has a wheelchair lift that can handle my motorized wheelchair. That certainly qualifies me as disabled.

The problem with disability as we label it in this day and age is that it's not a natural state. I don't mean it's not natural to have a disability. It's very natural. It happens not only to humans, but to every living thing. But for some reason, we humans made a decision somewhere along the way that this natural occurrence of all life was not a good thing. Or maybe it was a good thing. It allowed some people to separate themselves from some other people.

I separate myself from you because you do not have a mobility impairment. You separate yourself from me because I don't have a communications impairment. I separate myself from you because you don't know what it's like to always live in pain. You separate yourself from me because I live a middle class existence. I separate myself from you because you don't have to have specialized equipment to get out of your house. You separate yourself from me because I have a little money. I separate myself from you because you don't know what it's like to be married. And on and on and on and on and on and on it goes!

The reason we have trouble defining disability is because it's a made up social construction enforced to apply a sociocultural, political label to a natural aspect of life. The reason we keep disability is because it separates us. For all the millions of people who make money off of us as long as we have our disabilities they have their jobs.

The reason we keep disability is because it separates us. As long as we have our disabilities then we have a reason to rail against a society that discriminates against us and forces us to be different whether we want to be or not. As long as we have our disabilities we can question why someone we don't know uses a "handicapped parking space" or an "elevator" or receives SSDI. We can also be assured that those we know are in the "club" deserve these "rewards."

Disability is not a question of labels, it's not a question of legitimacy, it's not a question of social constructions, or even a question of who deserves what and who doesn't. It's not a question of physical, mental, social, cognitive, psychological, emotional deficiencies or differences. It's a question of separateness. It's one more way we've figured out to separate groups of people. We, in this country, have had experience with this kind of separateness before and with the same disastrous results.

It was called slavery. We decided because people were of a certain skin color they were different and different didn't mean better, it meant inferior. We've made the same leap with disability. We've decided there are these conditions that we can give labels to and that therefore some people are inferior to others.

We're finding out as we try to define this amorphous term called disability that it's about as useful as trying to define someone by their skin color. It simply can't be done. That doesn't mean it won't be done. It just means that the merit of judging someone by their coloring is about as useful as judging someone by their disability.

What would happen if all the money that was spent on disability programs went into a general fund to make society equally open to everyone. All vehicles would be built to adapt to all known physical conditions. Same with houses, airplanes, busses, trains, etc. Anything left over could go annually to anyone who was classified as having a disability. You can bet that then the figure of 60 million or whatever it is today would quickly increase.

Will this ever happen? Not in today's society. Why not? Because our society is fueled by this need for separateness. And what does this separateness lead to? Anger! And what does anger lead to? More separateness.

Where does that leave us. I'm not Ed. I'm not in love with humanity. But I'm trying. Because as trite as it sounds I do believe the Beatles had the answer all those years ago: all you need is love. Well, maybe not all, but it sure it a lot better than living from hate. And we know from the past five hundred years of our history where hate gets us. We don't have a clue about love.

I think it's time we find out.