Margins Are Not For Cowards

by Cheryl Gibson

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Dans cet article, l'auteure joue avec le concept de "marginalité" et elle examine ce concept à partir des deux perspectives suivantes soit interne et externe. Vivre avec un handicap permanent est épuisant mais cela n'empêche pas que chacune d'entre nous puisse faire beaucoup avec sa vie aussi limitée puisse-t-elle apparaître.

Does being a woman and having a disability somehow marginalize me? I don't think so, except when I'm having a really bad day. Like the time I wanted to take my children on a holiday and found that Via Rail refused to accommodate me. Or the time I tried to attend a conference for Health and Welfare Canada and Via Rail informed me that the train was fully booked months ahead with tourists and they didn't have to keep any seats for people who couldn't travel any other way. The time I was in a wheelchair and asked for a cup of tea, only to be told to get my own tea on the other side of a wheelchair inaccessible room, has to near the top of the pathos scale. Major setbacks or minor insensitivities can make even a tough "cripple" like me wonder if it is all worth it.

What does it mean to be marginalized? According to my dictionary, it is derived from the Latin "merg" which means a boundary; it can also mean "a lower standard or limit of a certain quality." Perhaps these two have blended to imply that people who can't meet a certain standard are expected to stay outside the boundaries of civilized society. That is certainly how it feels to discover that the things I used to take for granted are now out of reach. What is even more frustrating is when society thinks they should be beyond my expectations.

I wasn't born with my disability. It is the result of a failed back operation, so I still have the expectation that I will be able to do the same things and go the same places—because I am very stubborn, I thought it was just a matter of figuring out how. The reality of a world that is made for the average person's needs is slowly sinking into my conscious mind. It is my subconscious that keeps insisting that there has to be a way around, over or through any obstacle or problem. Either that, or it is just a habit I developed early in life and have yet to outgrow. Whatever the cause, the effect is the same: I never stop trying to live a full life and am surprised when the rest of the world thinks I should be content with something less.

Before I had my operation, I was oblivious to the barriers that are created when a society is geared towards providing services for the majority. I didn't purposefully restrict the activities of women who could not walk, but I did wonder if all those handicapped parking spaces were really necessary. I assumed people who couldn't walk were fortunate to have ramps and wheelchairs and shouldn't aspire further than an accessible washroom.

At first, I fought the idea of a wheelchair, of a scooter and of two canes. Only when my "back was against a wall" because my legs wouldn't function, did I admit that I needed help. It was humbling to realize that I could no longer live my life on my terms. My mother claims that I was born on my own and have been on my own ever since, so the thought of using an "orthotic appliance," as they are euphemistically labelled, was admitting defeat.

It was even more difficult for me to resolve my feelings about depending on other people than it was to admit that I had to use a wheelchair. In my mind, a grown woman should be able to stand on her own two feet in every sense of the word. When a feminist who has spent all of her life insisting that she could top any man has to ask for help, or worse yet, accept it graciously, then it is time to rethink all her assumptions about life.

I can be marginalized by my own attitude or by the constraints of a world designed around the needs of those people who can sit and walk and carry things. Those of us who have to spend a great deal of time lying down would have been better off in the Roman Empire; in this century we need to drive cars, ride in trains, or work at a desk. My internal struggle to come to terms with a disability is different from the external struggle of fitting into society.

My philosophy, which grew out of the turmoil of facing a permanent disability, rests on the cornerstones of interdependence and balance. I still, especially as a woman with a disability, need to feel self-sufficient, competent, and useful. Being thought of as attractive wouldn't be bad either, but I'm not sure if society is ready to see people with disabilities as sexual beings.

Interdependence requires a delicate balance of pride and humility, common sense and resilience. Last month, I was staying in a hotel with my daughter, Jennifer, who is hearing impaired. We were in town for her hockey tournament and had to haul hockey equipment plus the usual luggage into the hotel. When we were looking for a place to park, we noticed that someone had parked in the handicapped parking spot without a permit. Jennifer went to the desk and confronted the manager about not enforcing the parking by-law and about having only one space. The manager found a parking spot for us. Later, Jennifer decided to watch a movie on TV and asked me to phone the manager to find out if they had closed captioning for deaf customers. I did and they didn't, but the hotel at least became aware that it was an important issue for some people. This is a classic example of being interdependent. I was able to help her when she couldn't use the phone and she was able to help me when I was in too much pain to confront anyone.

Balance is something which is very hard for me to achieve because it means leaving things out or paying for them later. That is a difficult choice for someone who used to want it all. There are times when I choose to do something, like going to my daughter's graduation, even though I know I will be in more pain at the time and for several days after the event. I have discovered that trying to do things that I used to take for granted is impossible unless I am willing to give up something else. It is a lesson that all women learn, but it is more brutal for some of us. Living a balanced life is crucial to accomplishing anything. I am always asking myself "How much do I need this and am I ready to pay the price?"

My work used to give meaning to my life. It defined me as a mother and a psychologist. Not to work is to become invisible, so I have created projects to occupy my mind. There are times when I get frustrated and have to admit that the work is too physically draining, but then I remember that I really should be grateful because two years ago I couldn't write at all. Trying to work within my own limits puts me completely out of step with the rest of society, but not working renders me obsolete.

My struggle to find meaning in my new life as a woman with a disability has taken time. I needed to understand, at the deepest level, that there were real limits which I couldn't wish away. Then I had to find a way to incorporate those limits into my life without becoming dehumanized.

Creative expression in writing poetry, prose or in art became my route to wholeness. I learned that I can avoid being marginalized in life if I refuse to recognize that margins exist. I still get irritated when I can't do something that everyone else takes for granted, but I'm also grateful that I have the opportunity to live a full, rich life within the parameters that I have been given. I can create meaning within my life. Finding joy and possibilities takes greater creative effort when the options are limited, but it also provides greater satisfaction. I suspect that most women have had to face this restriction of opportunities at some time in their lives. When society defines us as marginal, for whatever reason, it can be a signal to fight back. Margins are not for cowards.

Cheryl Gibson is a psychologist who specialized in educational psychology and neuropsychology until she had a back operation in 1989. As a result of the operation, she was left with a permanent disability. She is unable to sit, to carry things, or to walk without canes. She can no longer work, drive the car (except for short distances), or even do simple things for pleasure such as go to the theatre or restaurants, etc., and she is in almost constant pain.

Winsom, *Me, Myself and I.* Acrylic on canvas, 22 cm x 28cm.