Having A Disability 'Sometimes'

by Sherry L. Peters

Lors d'entrevues de longue durée, cinq femmes qui présentent des handicaps physiques, dont entre autres, la sclérose en plaques, la dystrophie musculaire et le lupus, ont partagé leurs expériences particulières de femmes qui présentent un handicap intermittent, c'est-à-dire un handicap qui n'est pas toujours visible pour les autres. En se remémorant leurs expériences dépendamment de la visibilité de leurs handicaps, ces femmes expliquent comment le fait d'être atteintes d'un handicap qui n'est pas constant est unique à sa façon et comment cela les rend perplexes face aux réactions changeantes des autres.

I am a woman with a disability exploring the experience of having a disability. For some, including myself, this experience is *not only* the experience of having a disability, it is the experience of appearing to have a disability *'sometimes'* in the eyes of others. Unlike individuals whose disability is unchanging in its visibility to others, individuals who are seen to have a disability 'sometimes' *lack consistency in the appearance of their disability,* although their disability in reality remains with them.

While physical disabilities are often separated into two categories—visible and invisible—I would like to suggest that in terms of appearance, some disabilities fluctuate between these two extremes—from visible to invisible, from highly visible to less visible or the reverse. The fluctuation may involve a change in the *degree of disability* (e.g. an individual's disability may go into remission with the disability becoming invisible), *circumstances* (e.g. an individual's disability may become less visible if they are sitting rather than standing) or *environment* (e.g. an individual's disability may become more visible in certain locations such as a recreation facility). One woman, Donna, who uses a variety of aides including a cane, walker, and wheelchair says,

> *Every day is different. Some days I feel a little bit more loose and relaxed and able to get around more, and other days I feel like... my whole body is hurting.... Every day is different.*

The frequency and extent of changes in the visibility of one's disability are of course unique to every individual, as are the changes in the responses of others and the individuals' reactions to these responses.

Five women were interviewed at length to explore their experiences of having a disability 'sometimes'. Their disabilities include multiple sclerosis, muscular dystrophy, and lupus. Diagnosis varies from soon after birth to adulthood. As these five women recount their experiences during times of change in the visibility of their disability, we can see how being disabled 'sometimes' can be complicated.

Cheryl has a disability which fluctuates in visibility as she uses both a scooter and elbow crutches. She finds that there is not the same "negative connotation" attached to the scooter as there is to the crutches:

> *I think... a scooter to other people is almost a toy... it doesn't have the same stigma attached as say a power wheelchair or a manual wheelchair ... I get a lot of comments from people...like they'll ask 'how far does that go?' or [they'll say] 'I wish I had one'. Don't ever hear someone say... 'I wish I had crutches'.*

To Cheryl, others' sociability is clearly tempered at times when she uses crutches and her disability becomes visible after a period of being unnoticed.

The profound impact of receiving a negative response to this change in the visibility of her disability is well-illustrated in an experience she relates. While out at a nightclub, she had a man get a "whole different attitude" after he realized that she had a disability. Although she sees herself as "the same person" with or without the disability, this experience was sufficiently unsettling that she has since made a point of putting her "crutches some place that's easily visible so that somebody isn't gonna mistake it or not know that I am disabled." Such shock on the part of others leaves Cheryl "always *nervous* [when] going into new situations."

Fiona, who limps at times but does not use any mobility aides, senses other individuals' awareness of the moment-to-moment changes in the visibility of her disability.

> *People... look at me, I look fairly big, healthy... and then you stand up and [are] limping or dragging your foot or falling.*

She is greatly concerned about others' disbelief in her illness. She explains,

> *There's nothing to see in a lot of cases like when I was limping... people did probably notice but a lot of times the frustration is more so when you have quite severe symptoms and nobody knows... you're off work sick and people don't think you're sick.*

It troubles Fiona that some of her co-workers "might think that I made this all up, that I was faking it." She recalls a moment of sorrow after a co-worker commented, "Oh *must be nice* taking four months off" as though the time off were a vacation rather than recuperation.

Joann, whose limping changes with fluctuations in her illness and includes "days when I don't have... a visible limp," resists using any type of mobility aide as she does not want to make her disability more visible. She expresses a fear of having others stare:

> *You go in a nice restaurant and you're all dressed up ....I get up and go to the washroom, I feel like there are probably a few people who might be watching, staring, watching me limp to the bathroom and here I look like a fairly healthy young woman all dressed up in a nice restaurant and there I go limping off to the bathroom.*

Her fear of being stared at compels her to put off going to the bathroom until she returns home rather than risk being scrutinized by others. Even at an intimate family get-together, Joann senses a change in her family's awareness of her disability as she changes activity.

> *If I get up [from the dinner table] and I'm having a bad day and I have to limp to the bathroom, it's almost this imperceptible thing [or] communication going around and even if I've told them I'm having a bad day, they're all of a sudden faced with it. It's one thing for me to be sitting across the table and look fairly healthy and fairly active and then it's another for me to get up and start limping or that kind of thing where it's a more visible thing and then it kind of hits them in the face 'Oh ya she is sick.'*

Ivy wore braces on both her legs throughout her childhood until approximately four years ago. As she reflects on her experiences, she recalls her "obsession" with hiding her braces:

> *I'd always make sure my jeans were long enough... when [I] sat down because people would stare, it was so obvious... and as soon as you sit down, people look and they notice right away.*

She is acutely aware of how others have responded to her with and without braces.

> *You do notice the difference with the braces, with the visual thing and without... strangers I think are more apt to... approach you or not shy away from you.... I think people tend to not [approach] somebody who's got a real visible thing like that.*

The suggestion that she may need to wear leg braces again is repulsive to her.

Donna uses a number of different mobility aides depending on her need for assistance. She finds that people "notice [her walker] more than the cane and not as much as the wheelchair." While others' negative responses are often short-lived, they touch the everyday aspects of her life.

> *...You go down the street, you're walking with your cane or whatever and...because [you] look normal, people can't figure out what the heck is wrong with [you] walking with a cane or whatever... it really irks you know, [I] don't like being stared at.*

Donna is highly concerned about others' disbelief in her disability at times when it is largely invisible. She explains that as she is not "physically twisted up or crippled that you can see...people have a hard time believing it. If I had a cast they would even give me sympathy but they don't see it...." She further illustrates her predicament:

> *When I go to a parking lot at a shopping center and I park in the disability [stall], I stand up, get out of the car and everybody gets dirty looks ...because I'm young, what do I need a disability [stall for] 'cause I can stand and I should be wheeled in a chair or something.*

While it may or may not be what others intend and while the response from others varies for each individual, these five women's narratives reveal experiences of rejection. They recount times of change in the visibility of their disabilities which are filled with rejection in the form of scrutiny, apprehension, and disbelief on the part of others—sometimes. Responses to these women are in fact ever-changing: at times they are rejecting, at times embracing, and at other times indifferent. These stories provide examples of how the appearance of disability constrains women in relations with men, with family members, with co-workers, and others.

It is the very fact that individuals who have a disability 'sometimes' *lack consistency in the appearance of their disability* that makes being disabled 'sometimes' unique and makes the changing responses of others perplexing. Having a disability that is unwavering in how it appears enables one to anticipate others' responses. As we all search for consistency in our social experiences, then, individuals who have a disability 'sometimes' must struggle all the more. It is an experience of uncertainty.

While interest in the experience of having a disability is growing, those who have a disability 'sometimes' have been overlooked in the search to understand what it means to have a disability in our social world. The experiences of those who have a disability 'sometimes' and those who have a disability 'always' are not identical. For those striving to explore the experience of having a disability, to assist those who have a disability in their acceptance and healing and to help others to understand, further exploration of the unique aspects of having a disability *'sometimes'* is necessary.

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Sherry Peters is a Master's student in Sociology (Disability Studies) at the University of Alberta in Edmonton. Her disability, a fused hip which is the result of a car accident eight years ago, leaves her with difficulties with walking, balance, and ability to sit for extended periods of time—sometimes.