Marriage-able?

Cultural Perspectives of Women With Disabilities of South Asian Origin

by Lynda Nancoo

Le mariage est très important pour les femmes handicapées d'origine Sud-asiatique. Dans cet article, Shabana et Aisha soulèvent des questions sur l'impact culturel d'un handicap ainsi que sur le manque d'attention donné à l'aspect culturel de la vie des femmes handicapées. Elles espèrent que leurs témoignages encourageront d'autres femmes à partager leurs expériences dans leurs communautés respectives.

Immigrant women with disabilities are vulnerable to being used as a passport to Canada.

"I wanted to run away," says Shabana as she discusses how myths surrounding disability within the Pakistani community almost destroyed her self-esteem and confidence when her parents began searching for a suitable marriage partner for her.

> *My disability was only discussed when for example I would go to Pakistan and would trip over things and they would say things like, 'Oh! you are blind, aren't you, oh'.*

Marriage is an important issue in Shabana's culture. Seeking a marriage partner in this community is much different from the western experience. In the Muslim culture, parents from both sides arrange a "meeting" where both families and prospective bride and bridegroom meet for the first time. Prior to this, the parents of both families will research each others' background, religious faith, extended family, education, employment, etc. Although both families are present during the "meeting," the couple is left alone for a while, where they can speak freely to each other.

Parents will go to extreme lengths to find suitable partners. Shabana was flown around the world for arranged meetings. She recalls one of these meetings with bitterness because women with disabilities are seen as unmarriageable.

> *My parents took me to New York. As far as they were concerned this guy was ideal. He had the qualifications they were looking for, he had an MBA and was working and he had sent his picture. My mother took me shopping like usual (for dowry purposes).*

When alone, Shabana decided to test this perfect partner and told him about her vision disability. "He tried to be sweet about it but I knew that it was going to be a problem."

Two weeks after returning to Eastern Canada she received a phone call from him. He told her he had talked to doctors and friends about her disability. The majority of them told him there was a possibility that their children would have a disability.

> *I told him that it was the best thing to talk about my disability and if you feel strongly about it then it's best you don't call me again.*

He never called again, and the rejection devastated Shabana. "If he had rejected me for any other reason, I wouldn't have taken it as hard."

Shabana was born in Pakistan with a vision disability called "retinitis pigmontosa." Retinitis pigmontosa (RP) is a hereditary degenerative disease of the retina. People with RP usually experience a loss of peripheral and night vision. It can eventually lead to blindness.

Shabana's disability is invisible most of the time. She does not use physical devices to maintain independence, although her vision is greatly reduced at night.

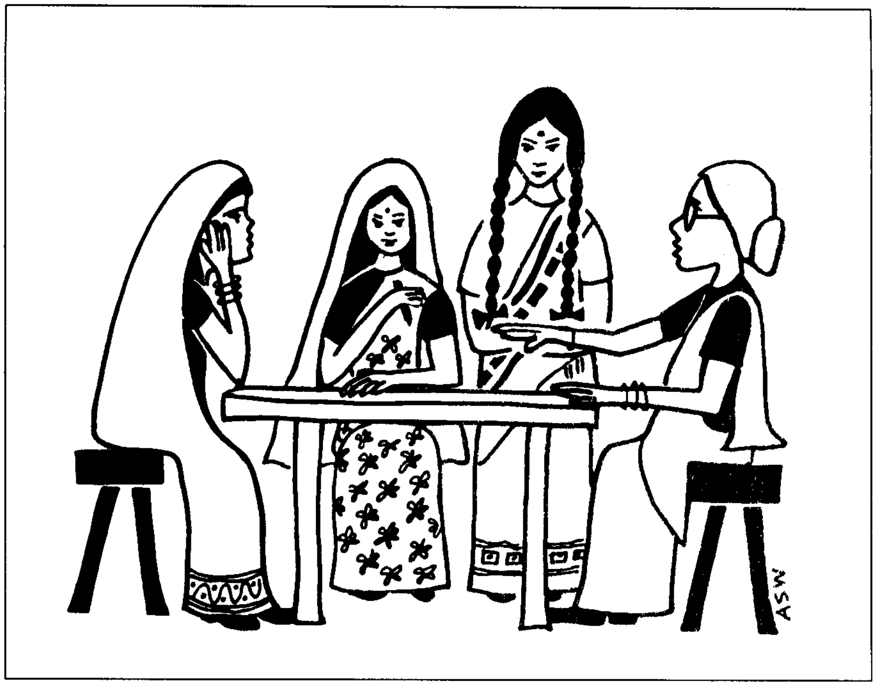
After the rejection, Shabana rushed into marriage with a good friend who knew of her disability.

> *...We knew each other from the time we were children. In three months time we were married. Suddenly I realized what I had done and thought, 'why did I do this?'*

Two years later, the marriage produced a healthy baby boy and a divorce. "I felt that I used my first husband, who was also a good friend, to prove to myself that I can be accepted...."

In part, Shabana blames her culture for what happened.

> *I wish disability could be more open and accepted. It's not something we should feel guilty about. It's not a fault of ours.*



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The disability rights movement has not concentrated on the cultural impact of disability.

> *Once we're made to feel better/good about it then we can feel good as individuals and from there on we can go on to other aspects of our lives. We need this confidence. Marriage is a big issue, a very big commitment.*

In Shabana's community, disability is rarely discussed. Lack of education and awareness means that people in the Muslim community will continue to hide their disabilities.

Regaining her confidence, Shabana married again. This time, the couple allowed enough time to learn about each other. She is still married to her second husband and now has three children.

> *What I have gone through is twice as hard as someone without a disability. I felt I had to try twice as hard.*

Her second husband knew about her vision disability prior to their marriage, and accepted her the way she was.

If it wasn't for her husband's support and sensitivity, Shabana feels she would not have been able to cope as a mother with a disability. She enjoys being a mother, and talks fondly of her three children (none of whom have a vision disability) and passionately about her husband.

The next hurdle is to tell her children about her disability. Though they recognize that 'mommy can't see too well,' she feels that her children are entitled to education about disability issues. By making them aware of her disability she hopes that they will be openly accepting of all people with disabilities.

> *My children help me a lot. When we go out they say, "Mom let me hold your hand, Mom there's a step here," even in broad daylight! ...But lately, I want to tell them about what is medically wrong with my eyes. I feel my children should be very secure. Maybe it's my inner feeling. I want them to know.*

She also intends to keep discussing her disability openly at the family dinner table. "[My parents] have been very supportive but the culture is what's preventing them from fully accepting my disability."

Like Shabana, marriage is very important to Aisha, who longs to find a suitable marriage partner. "Men don't look upon us as potential partners or wives, or they don't look upon us as desirable or capable of sex."

Myths that women with disabilities are sexless, desireless, and incapable of childrearing and childbearing leaves many women like Aisha in despair.

> *...From a Muslim cultural perspective, culture itself stigmatizes people with disabilities. I have to marry within my religion. That's extremely important to me. It's difficult to get partners within the Indo-Caribbean community because of stigmas toward people with disabilities.*

Unlike Shabana, Aisha's disability is very visible. Her electric powered wheelchair is a dead giveaway. Aisha was born with polio in the Caribbean. She talks about her desire to get married, but unfortunately, negative stereotypes of disability within her culture prevent her from finding a suitable partner.

> *The perception is that, due to my disability, I would not be*

able to do things like non-disabled women, such as, I won't be able to take long romantic walks, won't have children and wouldn't be able to have as many children as they want."

When Aisha told her parents she was thinking of marriage they were very supportive. They started to talk to friends, family, community members, and others. Aisha looked forward to the "arranged meetings."

She eventually decided to return to her homeland in hopes of meeting someone. Aisha did find a suitable partner there. She married him and upon returning to Canada immediately did whatever was necessary to bring him to her.

She was devastated when she learned that her perfect partner only married her to immigrate to Canada. Immigrant women with disabilities are very vulnerable to being used as a passport to Canada. She remains optimistic, however.

> *There are good people and bad people. I had to make a decision in a couple of days. I got married. After I got back and we started corresponding on the phone, I realized he wanted to get married to me to come to Canada and nothing else. So I called it off. I stopped the sponsorship....*

Fortunately, Aisha's parents supported her decision to end the marriage. Her disappointment has not stopped her from wanting to experience the roles of wife and mother. She wants a partner who will understand and accept her the way she is. But why is marriage so important?

> *I have an extended family; people who care about me, lots of friends. What I don't have is a husband. From a religious point of view I can't have a boyfriend. I am not allowed to go on dates. My religion considers marriage as half of fate. For me, marriage means fulfilling half my fate. Also, I have a strong desire to have children.*

Loneliness is often a major issue for people with disabilities. Because Aisha is a wheelchair user, spontaneity is almost impossible. She must book accessible transportation at least four days in advance. Aisha does not go to parties, bars, or other social events or gatherings where alcohol consumption and smoking are practised because they are not compatible with her religious and cultural beliefs.

Western culture does not concentrate heavily on promoting marriage, and the disability rights movement has not concentrated on the cultural impact of disability.

> *The disability rights movement in Canada has done nothing to raise awareness of the marriage-ability of disabled women. They are concentrating on issues such as, violence against women, building self-esteem, sexuality, but not on marriage.*

In Aisha's culture marriage is the norm. She has watched sisters and brothers, friends, other family members, people from the mosque and others, marry and have children. She feels that her community should be educated about issues surrounding disability. Perhaps if more Muslim people with disabilities spoke up about exclusion, disabilities would become more acceptable.

Marriage, says Aisha, makes you think about your physical appearance. What is a beautiful body? Can a woman in a wheelchair be beautiful? Can a man be attracted to someone like this? What would make him more interested? What would his concerns be? Will he be open about all of these concerns? And what about inner beauty? These are questions many women with disabilities don't have answers to.

Both Shabana and Aisha have chosen to maintain their identities as Muslim women with disabilities living in Canada. They both agree that the cultural impact on marriage should be discussed more often, and that communities like theirs should be better informed about disability issues. Also, Canadians must be more sensitive and accepting of cultural differences. This will help encourage the acceptance of people with disabilities and most of all, it will promote the marriage-ability of women with disabilities.

The names and places of residence of the women in this article have been changed to protect their identities.

Lynda Nancoo is a freelance writer/researcher. She has written on issues such as disability, immigrant women, poverty, housing, social policy, education, employment, self-help, transportation, and racial minorities. She is currently working on a book about disabilities.