

# Disability and Relationships

by Tracy Odell

*L'auteure décrit comment les perceptions concernant les personnes handicapées et leurs relations inter-personnelles affectent la vie des femmes handicapées. En partageant son expérience personnelle, l'auteure explique comment elle en est venue à accepter son handicap et à développer une relation intime avec quelqu'un.*

There was a long time in my life when I thought I'd never have anything to say on either the topic of sexuality or the topic of relationships. I was born with a disability, which wasn't noticeable until I was old enough to walk—and didn't. My life moved forward in every other aspect, such as school and making friends, but relationships—you know, the personal ones, seemed to elude me.

I was a "late bloomer" in that it took a long time for me to develop an intimate relationship. Why would it take longer for me to fully develop as a person as compared to my non-disabled peers?

Common wisdom is that you have to love *yourself* before anyone else can love you. Is it very easy to love yourself if you happen to have a disability? It should be. But it is, in fact, *very* hard for us to love ourselves as we are. At least it was in my day.

I was fascinated recently to find out that the first documented person with a disability was a Neanderthal known as "Shandy." Shandy lived, loved, and died many millennia B.C. He may have had spina bifida. His skeletal remains show he had one small arm and some injuries which had well healed over. He was found amid objects from a hearth. Archaeologists and anthropologists can tell us that people who tended the community hearths were valued and respected, even revered. So certainly in 50,000 B.C. or so, it was possible for someone who had a disability to be a valued, contributing citizen. I don't know about Shandy's personal life, of course, but his bones tell a wonderful story of how someone with a disability was the hearth, the warm, vital, living heart of his community.

Much later in time, people with disabilities were regarded differently. In nomadic societies, people needed to be quick and agile. The hunter-gatherers were valued, not the hearth-tenders. The Spartans were an example of a society that valued strength and perfection. They're the ones who left their children alone on a hilltop overnight as a test of their strength and worthiness. Children who survived this test were named and joined the Spartan society. I used to wonder: How would I have slowed them down if they had had to carry me everywhere! I guess I would not have been *allowed* to live, if I'd survived the hilltop test.

A quick review of the Bible was hardly comforting either. Biblical references to disability were few, but got a lot of press in my circles. People with disabilities appeared in the Bible to demonstrate the almighty power of God to do as He (She) wished. Blindness was used so often as a metaphor, I wondered if they were truly talking about people who could not see physically or who would not see spiritually. As a ten-year-old Bible scholar, these metaphors were mixed and confusing. If God didn't have to accept people with disabilities, did anyone?

You need to know that when I was growing up in the mid-sixties to mid-seventies, the popular and accepted mode of treatment for people with disabilities was life in a institution. I met many other kids there who had disabilities. Some could do no more than me, some could do less. I lived in an institution from the time I was seven until I was old enough to sign myself out at eighteen. For the life of me, I couldn't figure out why some of these kids were there. They were so *capable*. At least for my sister and I, our parents had to do quite a bit to look after us. They'd have to help us get up, go to bed, use the washroom, and so on. Kids become increasingly physically independent starting at age two, but someone would always have to help us with everything physical.

I guess the crunch came once mom and dad separated. We were older, we needed wheelchairs and backbraces which my parents couldn't afford, and we were rejected both from the neighbourhood school (too sick) and the segregated school (wrong disability). So off we went to an institution, run by nurses. My mom called it *The School*. This institutional hospital, home, and school was known as "The Home for Incurable Children" when my sister and I went to live there. She says the first time she saw that sign she felt like *Oliver Twist*.

My life in the institution revolved around rejecting the disabled part of myself by "improving" it through therapy. All of us were taught it was better to use crutches than a wheelchair, better to limp along off-balance than use crutches. The goal was to look as "normal" as possible. Many of us learned later that function was better than appearance. The nurses snubbed my pleas for a motorized wheelchair that would give me effortless mobility, saying it was better to use my arms. Pushing a chair wore me out so much, I was good for little else halfway through the day.

In my day, people with disabilities were rejected on every major front. Many of the kids I met in the institution were abandoned by their parents who could not deal with a child who was not perfect, or who needed more attention. At least our family stuck by us while we were there, but I saw the damage done to other kids literally orphaned at the door. Some families truly

thought the child's disability was a punishment for their sins. Oddly, others used us for redemption through charitable activities for our benefit.

Add to this the use of disability to show evil—Captain Hook was more sinister because he had a hook for a hand, villains are disfigured by scars, or missing limbs (Eddie in the *Friday the 13th* series); or the use of disability to draw out pathos—such as the Hunchback of Notre Dame, who was feared, then understood, or Jill in *The Other Side of the Mountain* and other movies like it. As difficult as it was at times to be born with a disability, sent away from home, and raised by strangers, how awful to become disabled when you weren't *supposed* to be that way.

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I struggled with all of these messages as I was growing up. Intellectually, I understood what my disability was and how it was genetically introduced. Yet emotionally, I thought people with disabilities were a mistake, or else God wouldn't have been busy curing all those people in the Bible; or that we were just barely tolerated—allowed to live, but not allowed to interfere with anyone else's freedom; or sad but accidental creatures of chance. It's a wonder I emerged with any sense of self-concept at all.

With all this history, literature, and our portrayal in the media, what's going to be in the back of anyone's mind when meeting someone with a disability? What would be going on in the back of a boy's mind that I might meet who was a volunteer at the institution or an able-bodied classmate at high school? Would he imagine me as a potential girlfriend? wife? friend? Would he feel sorry for me? Would he only like me if he was weird?

I remember being 10 or 11 years old and starting to think about my potential as a complete, adult person. There was a nurse I liked and I remember asking her if I'd ever get married and have children. She was very doubtful. She felt a man wouldn't want the burden of looking after me; he would want a wife who could look after him. Besides, how would I dress my children if I couldn't even dress myself. Now, you need to understand she said all this very kindly. There was no hint of animosity at all. She wanted to help me to learn to accept my circumstances and their realities. She did not wish to pump a child up with false hopes for the future. I think because of all this, I always remembered this little heart-to-heart chat. Because she was so sincere, I not only believed her, but I limited my sights and expectations based on the "facts" laid out for me.

I figured that I probably would never marry, but if I ever did, I'd just let my husband have a mistress so he wouldn't feel deprived. Now, as an adult who still has a disability, but also a career, husband, and family, I can afford to laugh at my naiveté.

Friends teach us what is likable and "cool" about ourselves. Growing up in an institution, we had two categories of friends: 1) kids on the inside, who were not all that important, and 2) kids on

the outside who we would live and die for.

My whole notion of what a friend was, was totally skewed. These outside friends were volunteers, dropping by once a week or on weeknights to do their good turn for society. This was *charity*, not natural, freely-given relationships. They weren't paid to be there, but they wore a name-badge. Also, we were friends within an artificial environment—visiting hours were over at 9:00 p.m. I always thought they were as sad to go as we were to see them leave. Our social life came to an abrupt halt at 9:00 p.m. to make way for the institutional routines and rhythms; their social life really began after they left us.

I got to go out to a regular high school, since the institution's

school only went as far as Grade 8. I was socially inept with non-disabled kids. I finally made a good friend part-way through Grade 10, but throughout high school I was never asked on a date. I figured I'd have to wait until university, where I could count on people's maturity to see the real me, through my disability, before I could start dating. But, I never had a date in university either.

It's a wonder that I ever met my husband, David, in the first place. Getting there was anything but smooth. In earlier relationships I probably put up with treatment that other self-respecting people wouldn't have tolerated. My poor self-esteem and low expectations for relationships affected my judgment, and I hung on too long, thinking it was the best I could do.

But as I started working, I gradually developed self-esteem. As I gathered competence and skill at work, my self-esteem increased.

Now, I have two children, with all the accompanying blessings and pains of parenthood. Some days I'd recommend it; some days I wouldn't. Parenthood has been another type of struggle. I have a high degree of acceptance and support of me as a parent from my co-workers, my friends, my daughter's teachers, doctors, and others I have met. My family, on the other hand, was initially very concerned about the physical demands of pregnancy, birth, and raising children. My family also worried that a mere man could never cope in a "mother's role."

By the time I was married with a baby on the way, I had been living outside of the institution for twelve years. It's ironic that it took me the same length of time to throw off all its baggage, year for year.

I lived in an apartment where attendant support was available. Someone who was not a nurse would come and get me up in the morning, help me go to the washroom, go to bed at night, and perform other routine household tasks. My pregnancy met with a low degree of acceptance from the attendants. They assumed the baby would not be looked after properly and that I would put extra demands on them to help me do it. The attendants could not make the transition easily from me as a single person with a disability to being half of a couple with a baby on the way. On top

of dealing with my own anxieties about what I was doing and what I was in for, they made my day-to-day life a living hell. I had to move out and search for another setting where I could be accepted as doing a perfectly normal and human thing.

Once I was able to move to another attendant support service setting, where staff got to know us as a family right from the start, I had no further problems with attendants accepting us. When I became pregnant for the second time, the attendants were jubilant. What a change! Since my first pregnancy had gone well, and little Katie survived we novices as parents, my family felt more comfortable about our having a second child as well.

My husband, David has been the primary caregiver for both of our daughters. It is not an option for me to be home, so I continue working.

All these experiences have contributed to my growth and development as a human being. Of course people with disabilities are fully human; we all start out that way! We need families to love us. We need friends to teach us how to care about other people. We need someone special in our lives to share ourselves with and with whom we can be intimate. We need to accept ourselves for all that we are; this helps others to accept us too. We need to be out there in the world, so even our very presence can raise awareness.

In our own unique ways, we need to leave new "bones" which show our own hearths, our hearts, and our "centredness" in our community. Perhaps we have focused too much on *independence*. Human beings are *interdependent*. We always have been. We always will be.

I've always felt like an explorer—pushing the boundaries of where others said we could go. It's almost as if I had to do the things I have done just to prove the common person wrong. Told I'd never do anything productive for a living, I did. Told I'd never live outside of a hospital, I did. Told I'd never walk, well, who needs to?

What people with disabilities need to work on is protecting our rights to have *choices*. We have not been given many choices in the past. Low public awareness and a poor perception of us has made inadequate service systems acceptable. We've been put on waiting lists rather than offered services which meet our needs with dignity. The people closest to us—our families, medical professionals, and our friends—have betrayed us with limited expectations. And many of us have sold ourselves equally short, believing the shallow possibilities others cast our way.

People with disabilities, more and more, are a powerful force to be reckoned with. We are getting better at making our needs quite clear, whether it's a need for services or uplifting relationships. If we wait for others to do it for us, it will never happen. It's up to us.

*This article is based on a keynote address given by the author on April 3, 1993 for the Ottawa-Carleton Independent Living Centre's conference on Sexuality and Relationships.*

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## JANCIS M. ANDREWS

### Deaf Mute?

*"What a pity—that couple can never speak to each other about their love."*

(Woman talking about a disabled couple).

This dance of fingers  
sheds veils of air, reveals  
ten times over  
the nakedness of my desire.  
My palms doubly celebrate you,  
inscribe my love  
upon the space between us, enclose  
tenderness, shape it  
like a flower.  
And though the world about us roars,  
this silence  
is our own private universe  
wherein I sow a promise: kisses  
falling like stars  
upon your mouth, each fingertip  
a white flame  
foreplaying Heaven, igniting us  
toward that wordless ceremony  
where you and I  
will blaze in pas-de-deux  
into the profounder silence  
that will be our bodies, singing.

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## WOMEN, SEXUALITY AND DISABILITY

### Peeling Off the Labels

"Peeling Off the Labels" was a symposium on women, sexuality, and disability which was held on May 30 and 31st, 1992 in Toronto. The summary of the proceedings contains reports on all of the workshops held at the symposium, addressing issues such as body image, HIV/AIDS, cultural differences, sexuality and parenthood, and lesbianism. It also contains other relevant articles.

The summary, *Peeling Off the Labels* (written by Shelley Tremain), is available from DAWN Toronto, 180 Dundas Street West, Suite 210, Toronto, ON M5G 1Z8. Telephone: (416) 598-2438.