Life through the eyes of a disabled person

My name is Catherine Marshall and I am 25 years old. I have ataxia-telangiectasia (A-T), a neurological disorder which affects my balance and coordination.

Everyone gets frustrated from time to time, but to learn that you have a disabling condition has a major impact on your life. Before I was diagnosed as having A-T, I was an active, outgoing child doing the normal things children do. During my time at junior school, I began to take a keen interest in gymnastics, where I gained three certificates and won a bronze medal in a school competition. However, my balance began to deteriorate and I started to have problems with my coordination, and eventually I was diagnosed with A-T. I was devastated at this prognosis, as it meant I would have to give up my love of gymnastics. I now belong to a youth dance company called "Cando II" for disabled people and able-bodied people which makes up for giving up gymnastics.

It is an anxious time for anyone trying to find employment, but in my experience it is a long and frustrating process. I left Lord Mayor Treloar National Specialist College determined that I would have no problem finding employment as I had passed the Advanced Level in Health and Social Care with distinction, but my hopes were soon dashed. I have had several people who are assigned to help people with disabilities find employment, but they haven't done anything. It is disheartening to think that I worked hard at college and I have got nowhere. I often feel that if I didn't have a disability I would probably be employed and not be in this situation that I am now.

Life being disabled has its ups and downs, but so do other people. Many people have the ability to do what they want, when they like, but being disabled can have its limitations. At times I get very frustrated by not being able to do things other people take for granted such as walking unaided or planning a journey. Sometimes I think to myself that I should be grateful for what I can do because I could be a lot worse off; at least I can still walk a little and can do some things for myself. However, I like my own independence and find it frustrating when I have to depend on others. Having a disability has also affected my social life. I do not have friends my own age who are willing to look after me and take me out. This gets me down at times, but I just have to make the best of things and "count my blessings". I keep busy by doing voluntary work twice a week, shopping, and going to the gym. I have also been on holidays abroad and in the UK.

Everybody is different, so why is it that some people stare? Is it because of curiosity or ignorance? In my experience, it is usually the latter, and I find

Paediatricians may be forgiven for not extending their sights beyond childhood. But the disabled child, surrounded by willing friends, family, therapists, and carers may become an adult abandoned by at least the last two of these; and our contributor reminds us that even after decades of being a subject of curiosity it still hurts. How effective are we at ensuring progression to adequate "adult" services?

Ataxia-telangiectasia

Why is it that you stare
Is it because I'm in a chair
Or is it because you really care?

Are you looking for respect
Are you feeling some neglect
Are you trying to understand
Are you trying to lend a hand?

Ben Gorton
BenGorton@orpheus.org.uk

that girls are worse than boys. People who stare at me make me feel insignificant and self-conscious, but I realise they are doing it because they see me as different to them. I often put this down to lack of knowledge and understanding. The more people stare, the more self-conscious I become and this in turn makes me more aware that I am different. I find that people who are disabled themselves or have disabled relatives understand me more and therefore accept me for who I am.

I think if society accepts everyone is different, the world would be a better place. People need to change their attitudes towards others and not make pre-assumptions about people who are different to themselves. If the government were to enforce better provisions for people with disabilities, this may improve their lifestyles.

Catherine Marshall

Correspondence to: Dr H Marcovitch,
Syndication Editor, BMJ Publications;
hmarcovitch@bfinetnet.com

Call for papers

10th European Forum on Quality Improvement in Health Care
13-15 April 2005, ExCel, Docklands, London
For further information on how to submit your paper please go to:
<http://www.quality.bmj.com>