

## Christine Barton

When I introduce myself I don't usually start by saying I am quadriplegic. I tell people about the ways in which I am involved with health and social care. This gives them a clear idea that I play a very active role both locally and nationally, in other words I am a busy person. I can only be a busy person working for my community and enjoying being part of decision-making, if I have a lot of support from people and things. As this conference is about the things (equipment) I will begin by saying that I have a progressive long-term neurological condition (MS) as a result of which I am quadriplegic.

I started to need very minimal support (a walking stick) way back in 1985. As my condition is progressive my needs have grown over the years as the severity of the impairment has increased. I am now very dependent on technology as it is partly this that enables me to lead an independent life (and safeguards the backs of my personal assistants).

To help paint a picture of what this means in terms of equipment and adaptations I've made a list of all the things I have and use every day. Although this conference is about equipment I have included adaptations and wheelchairs because unlike a great many local authorities and the government I need to consider both together, not separately. I have:

- Adapted my home to give me a wet room with a level access shower and a wheelchair accessible hydraulic platform lift to get to the floor level of my bungalow (Sheffield is built on hills, they can't be ignored!)
- Built-up the conservatory to the same level as the house and put in ramps to give access to every part of the garden
- Installed a ceiling tracking hoist and a specialised bath with an electric seat and a moulded bottom, the bath not mine!
- Purchased a wheelchair accessible adapted vehicle that enables me to travel in the front passenger position in my wheelchair
- Adapted the garage to allow the vehicle with its ramp to be parked next to the front door

I did not qualify for any assistance with any of the above and have sourced and financed them myself.

In addition I have:

- 3 wheelchairs - 1 manual, 1 electric and an electric chair that is suitable for outdoor use and long car journeys
- a tilting manual shower chair
- voice recognition software on my computer
- environmental controls
- a portable hoist
- a recliner chair with 2 Repose pressure relieving cushions
- a specialised electrically profiling bed

- an alternating air cell pressure relieving mattress
- a portable profiling chair bed for hotels with a pressure relieving  
Repose mattress
- a voice-activated mobile phone

I also have a variety of small items, e.g. a stand for books.  
And I employ 5 personal assistants.

From this considerable list the only items supplied by the NHS or social care are the portable hoist, the shower chair, the Repose cushions, the manual wheelchair, the mattress and the environment controls. Being disabled is expensive and for me this is in the region of £150,000 spread over the years.

The hoops that an individual needs to jump through in order to get a piece of equipment or an adaptation are bureaucratic, expensive, create unnecessary mystic (when were you last assessed and told what kind of TV you should have!), reduce choice, are often means tested and can be seen as a charitable handout. I am very much in favour of a retail model where people are assessed to give them access to limited budgets, but then provided with a direct payment to purchase for themselves what they need. This system would need to be supported by independent centres where people could see equipment and get advice without being pressurised to buy.

There is more to a retail model than it just relating to provision by public organisations. The items that I have needed to purchase are very expensive, e.g. wheelchair £13,000, and they are made more expensive because they are only available through a small number of specialist suppliers. And yet we live in a time when the population is made up of an increasing number of older people and improvements in technology mean that people with severe impairments receive life-saving medical treatment. This means there will be higher demand for items to support daily living. A retail model that moved supply from specialist suppliers into the High Street would bring down the cost and make them much easier to find to say nothing of reducing the stigma.

As soon as there is competition consumers have greater choice and the price comes down.