

ADEQUATE TECHNOLOGY

Alice Maynard Lupton, Equal Ability Ltd.

ABSTRACT *This paper examines the role of technology from the perspective of a disabled person. It draws on the real life experiences of the speaker and her friends and colleagues. It argues that technology, though useful to individual disabled people, should be as simple as possible, and used as a social tool, rather than an individual intervention.*

Having been disabled all my life, I have a vested interest in technology for disabled people. I want to look at the use of technological solutions for the everyday problems of disabled people from two perspectives - first, the focus on the individual nature of solutions, and secondly, the over complexity of many of the solutions provided. This paper is written from a personal, (and indeed UK-based) perspective. I hope that my experience echoes that of other disabled people here, and informs the practice of those of you who are professionals in the field.

I have a neuro-muscular impairment, called Spinal Muscular Atrophy, which weakens all the muscles of my body, and is degenerative. I use an electric wheelchair, and rely on lifting equipment, converted transport, and many electrical aids in the home. I have always had a reasonably healthy distrust of "gadgets", and prefer the simple solutions to the more sophisticated wherever possible. My sister has the same condition, and is also an electric wheelchair user.

My sister and I run a consultancy specialising in disability issues. Our company, Equal Ability, works with organisations that want to integrate disabled people more effectively, with individual disabled people, and with organisations of disabled people. In our work, we encounter many instances of good and bad "disability technology".

I want first to look at the whole issue of what is a disabled person. This is fundamental to the good design of aids and equipment for

disabled people. Traditionally, disability has been viewed according to the medical model. This model of disability determines what disabled people can and, more importantly, cannot do by virtue of their medical diagnoses. The medical model implies that disabled people function in an inferior way to able-bodied people because of their medical condition, and are thus less adequate. Disabled people, according to this model, cannot participate in mainstream society *because of their medical condition*. Understanding that this is, and has been for over a century, the way that disabled people have been viewed, is important in understanding how the aids and adaptations market has developed, and the part technology plays in disabled people's lives.

Because disabled people have been viewed as less adequate on account of their lack of some function, the focus of technology has been to "normalise" disabled people - to restore or modify the "malfunction" so that they fit into, and can participate more fully in, mainstream society. This notion of normality is, however, a hostage to fortune. It changes as society changes, as governments come and go, and the frontiers of science are pushed back. Indeed, "normal" is best defined as all that is not "abnormal" and, in circular fashion, "abnormal" is whatever society considers unacceptable *within that culture, at that stage of its history*. Furthermore, technological interventions are usually designed for the individual since, in this view, it is the disabled individual who has the problem.

Many disabled people now reject this view of disability, and have adopted instead the social model. The social model of disability states that people with impairments (i.e. some lack of bodily function) *are disabled* by society when that society fails to take account of their needs. Thus, as someone with a neuro-muscular impairment, I have a reduction in or lack of certain bodily functions, such as the ability to walk. It is

ADEQUATE TECHNOLOGY

not this lack of function that prevents me participating fully in society - it is the way that society is organised that actively *excludes* me. Thus I *become disabled* when my workplace has steps, rather than a ramp or flat entrance. Someone who has diabetes *becomes disabled* when her employer refuses to allow her to take food when she needs to.

One of the most encouraging consequences of taking a social model approach to disability is that disability can, at least in most instances, be eradicated. But the focus of the social model is that it is society that needs the technological intervention, rarely the individual.

It may seem a subtle distinction to make between providing technological solutions to assist an individual disabled person to function within their existing environment, and providing technological solutions that remove the disabling barriers in that individual's environment. It is nonetheless an important distinction if disabled people are to gain self-esteem and empowerment.

Imagine that, instead of lighting on every street, people had to apply to the welfare services for a lamp to provide them with light at night. Street lighting is a technological solution to a special need that seeing people have. But it is a solution that has been applied to the environment, rather than individuals.

I have no wish to belittle the technological developments that have revolutionised individual disabled people's lives. And sometimes, an individual solution is the right solution. But each disabled individual then has to have a solution - increasing the time, energy and cost overall. And because of the way that society functions, many disabled people miss out on the solution, because they cannot afford to pay, they are not considered "needy" enough, their government does not offer that as part of the welfare service, and so on.

Indeed, in the UK, one of the reasons that

technological developments have centred on the individual, is the financial incentive. Successive government policies have focused on funding for individuals. Employment schemes provide money for aids and adaptations for individual disabled people who have obtained employment - the aid or adaptation goes with the individual, not with the job or company. This in turn encourages developers to direct their efforts at technological solutions for individuals - that way they know they will be paid.

Or will they? A further problem for disabled people is the cost of equipment and adaptations. Something may suit all their needs very well, but not their bank balance. If they are lucky - as I was in obtaining an electric bath hoist through our local Social Services - they will be able to get some kind of welfare assistance, either through statutory services or through charity. This is fine for the disabled individual, but is unlikely to be so popular with the supplier. In the UK, disabled people are not trusted with the means to pay for equipment and adaptations. Suppliers often have to wait for extended periods for payment, particularly where statutory services are concerned. This is damaging for their cashflow - the lifeblood of commerce - and administratively costly. And in the long term, it is damaging for disabled people. If manufacturers and suppliers were paid on time, their internal costs (cost of borrowing for materials already purchased, administration costs in chasing payment etc.) *would* reduce, and the cost of the products *might* reduce.

I say *might* because where a disabled person is not the payer, but is the user, marketing becomes more complicated for the supplier, and pricing is affected. Statutory services, and to some extent charities, can afford higher prices than individuals. And those of you involved in the commercial side will recognise that price is often dictated by "what the market will stand". Individual disabled people's say in "what the market will stand" is very limited.

ADEQUATE TECHNOLOGY

A common excuse for the astronomical cost of disability equipment is that the market is small. I find it difficult to see how that justifies some of the apparent mark up on products. One of the simpler solutions I have seen is used by a friend who has CP and has difficulty eating. She has a spoon on a stand, with a series of weights and springs, that enables her to feed herself. The cost of the materials can be little more than £100 sterling. But the selling price for this rather cumbersome looking, and not particularly portable, place setting is around £700 sterling. As an unemployed person on Incapacity Benefit (a UK benefit for people considered unable to work), she cannot possibly afford even one of these. And since they are not portable, she really needs three - one at home, one at the Centre she attends a couple of days a week, and one at College.

Because solutions are targeted to individuals, but some level of mass production is needed to make them financially viable, solutions are often complex, doing more than is required for a given individual, or in a given situation. As disabled people we crave - and often invent for ourselves - solutions that are as simple as possible, and as portable as possible so as to be of use in more than one context of our lives. Moreover, our lives are compartmentalised by professionals and solutions for different problems often do not fit together. Recently a disabled person discovered that his all singing, all dancing electric wheelchair was not compatible with the automatic clamp on his drive-from-the-wheelchair car.

Another consequence of the individual solution stretched to fit many people is that the disabled person is often expected to fit the product, not vice versa. This attitude is prevalent amongst disability professionals both in the medical and para-medical professions, and in the supply and sale of disability equipment. It serves to reduce further disabled people's self-esteem, as not only do they have "special" needs, but *their* special needs are more exacting than other

disabled people's.

The title of this paper is "Adequate Technology". Let me give an example of what I mean by this.

My sister finds it difficult to eject a floppy disk from her PC. The social model solution would be to design the PC external disk system something like the Macintosh, where ejection is controlled by software, so that no physical activity is required other than removing the disk. Her solution is an individual solution, but simple and effective, using an everyday object - a pen with a flat top. This is one of those solutions that we and so many disabled people of our acquaintance have developed - simple, practical, eminently portable, cheap and readily available. Better still, no charities or government agencies need be involved in its implementation. *And* she can sign cheques with it!

Again, many people who were affected by Thalidomide were, as children, encouraged to use artificial limbs to "normalise" them. They prefer instead to organise their environment - perhaps using alternative technologies - so that they can function as they are, without artificial attachments.

What I'd like you to take away from this is: Who is the technology *for*, exactly? As someone who has worked in the computer industry, I know how seductive technology can be, developing more and more sophisticated solutions without reference to the end user. Don't expect disabled people to conform to your notion of normality. Find out what we really think about your solutions. Fix the environment, not the person.

Alice Maynard Lupton
Equal Ability Ltd.
170 Benton Hill
Wakefield Road
Horbury
W. Yorks
WF4 5HW
UK