

TECHNOLOGY, SELFHOOD AND PHYSICAL DISABILITY

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INTRODUCTION

[...]

This chapter addresses the issue of the interface of technology and physical disability, drawing on a qualitative empirical study involving interviews with people with physical disabilities. The dominant research question was to explore the ways in which technologies contribute to the meanings and experiences of the lived body/self with disabilities. The study sought to investigate the understandings, beliefs and experiences of technology on the part of the interviewees, to identify their attitudes towards particular technological applications, to examine the relationship between type of disability and use of technology and to identify factors which may inhibit or enhance technological engagement on the part of people with disabilities.

The theoretical perspective adopted employs aspects of both social constructionist and materialist approaches to examining issues related to physical disability and technology. The constructionist approach includes examination of the ways in which the body with disabilities is socioculturally constructed via representation and the reproduction of meaning (e.g. Shakespeare 1994). The materialist argument addresses the ways in which disability is a form of social, political and material disadvantage, including restricted access to resources such as technologies (e.g. Oliver 1990). The two perspectives are interconnected, because material disadvantage is in

large part influenced by the tenor of sociocultural representations of and responses to impairment: [...]

The severely damaged body, the body that is culturally designated as 'disabled' compared with other bodies designated as 'normal', remains subject to a high level of stigmatisation and marginalisation (Oliver 1990; Hevey 1992; Davis 1995, and Thomson 1997). Unlike the typically 'absent' status of the 'normal' body (Leder 1990), the body of the physically disabled person is constantly 'present' to observers in its difference from other bodies. As Davis notes, 'The body of the disabled person is seen as marked by disability. The missing limb, blind gaze, use of sign language, wheelchair or prosthesis is seen by the "normal" observer. Disability is a specular moment' (Davis 1995: 12).[...]

In a society in which people with physical disabilities are still commonly represented and treated as lacking, as 'deviant' or 'grotesque' bodies expected to conform to social structures and expectations of mainstream society (Shakespeare 1994 and Stone 1995), for many the opportunity to use technologies in creative ways may be compelling. From a materialist perspective, therefore, technologies may be regarded as offering a tangible way of redressing sociocultural disadvantage and marginalisation.

People with disabilities have historically been excluded from full participation in society and active citizenship (Abberley 1987 and Oliver 1990). Williams argues that 'The reality of life for most disabled people is not the heroic overcoming of dramatic obstacles, but the daily struggle with the mundane activities through which identity is expressed and confirmed' (Williams 1993: 103). Technology offers the potential to greatly facilitate such mundane activities. In the process it has implications for the ways in which people with disabilities construct selfhood and interact with others. By augmenting or substituting particular bodily functions and transcending time and place, new technologies offer people with disabilities the possibility of facilitating entry and participation into previously inaccessible activities and domains. Computer technologies, for example, may lessen the importance placed on physical prowess and allow greater entree into the workplace for people with disabilities. As such, they may go some way towards redressing the disabling features of many work environments (Roulstone 1993; Roulstone and Roulstone 1998a and b).

However, technologies also bear with them negative meanings and implications. Among some members of the Deaf community, for example, there exists a trenchant resistance to using such technologies as cochlear implants (Davis 1995 and Yardley 1997). In this context, technology represents an 'artificial' invader of the body and a disruption of the subculture of the Deaf community, forced upon people who do not want it by advocates who continue to represent deafness as problematic and 'abnormal'. In such a context, technologies may be offensively represented as a 'correction' to or 'normalisation' of impairment, or as allowing people to

‘overcome’ their impairments, an approach which Roulstone (1998a) characterises as the ‘deficit model’ of technological aid.[...]

This research is extremely useful in providing some recent accounts of the lived experience of using technologies for people with disabilities. However, it is limited to the discussion of mainly computerised technologies specifically in the context of paid employment. It therefore does not provide insights into the other types of technologies that people with disabilities may use in other contexts. It is this lacuna that the present study sought to address.

THE STUDY

An in-depth interview study was undertaken with participants living in the city of Adelaide, the capital of the state of South Australia. The study was initially funded as exploratory and small-scale, the first phase in a series of related projects into technology and disability. [...] Those people who came forward and agreed to participate ranged in age from 19 to 46. Seven of the participants had suffered paralysis from a spinal injury, four had cerebral palsy, one had a lower limb amputation and three had a visual disability [...]

The questions in the interview schedule were arranged around four topic areas: the participants’ broad attitudes towards and use of technologies; their ideas about the relationship between types of technology and bodily function or part; their negotiation of technologies; and their identification of barriers to the use of technology. Like Roulstone, we wished to avoid the ‘deficit model’ of technological aid, preferring to focus instead on the ways in which sociocultural contexts may be either enabling or disabling to the living and work practices of our participants. [...]

TYPES OF TECHNOLOGY USED

[...]

The participants all said that they used a broad range of technologies in their everyday lives. The technologies they used included both those that had been especially designed as an aid for a specific disability and those that were developed for the general community but were found useful by the participants in ways that were not necessarily planned by the manufacturers. The former type of technologies, for those with mobility problems and loss of limb function, included wheelchairs, modified household items such as doors that can be opened with a string by the teeth or by remote control and hydraulic lifts for getting in and out of bed or

chairs. The participant with an amputated leg used a prosthesis. The people with visual disabilities said that they used such technologies as canes, closed-circuit television for enlarging print, ultrasound sensors, a water leveller, a 'talking' clock and 'talking' scales to weigh food. While they all also used guide dogs, they debated whether or not dogs should be considered a 'technology', given that they are living creatures rather than machines.

It was evident from this group of interviewees that computer technologies were extremely important in their lives. Some computer technologies were very commonly and regularly used across the group. These included voice-activated or talking personal computers, email and bulletin boards or discussion groups on the Internet, electronic organisers or memo machines, lap tops and scanners. Some of these computers had been specially adapted for the participants (for example, with voice-activated mechanisms) while others had not. Several people said that they used hands-free or mobile telephones. [...]

THE BENEFITS OF TECHNOLOGY

Regardless of their particular disability, several major attributes of the technologies to which they had access emerged as most important to the interviewees. These attributes were communication with others, mobility, physical safety, personal autonomy, control over one's body and life, independence, competence, confidence, the ability to engage in the workforce and participation in the wider community.

For example, Jo, a 35-year-old woman with quadriplegia, said that she highly values the technology she uses 'because it actually allows me to control my own life and without it I actually have less control'. Jo went on to emphasise that:

Control means being able to do things when I want to do them and make the decisions that I want to make as much as I can without having to involve another person. [...]

Technologies also allow people to avoid the embarrassment associated with dependence on others for help with bodily functions. Sam talked about his discomfort about his urine catheter bag. He now has an electric device that allows him to empty it without another person's assistance. This meant that he was able to 'do that in a way that I don't have to rely on other people to do it. It's given me a whole larger range of independence and being able to do it in a way that is, can be reasonably discreet'. Jo

also talked about her difficulties in relation to the elimination of bodily wastes. She commented how in an ideal world she would love to be able to access a technology that allowed her to toilet herself:

For me the nicest thing would be able to get on and off the toilet by myself, if I could do that. It actually doesn't bother me that I can't walk and I've often said, 'No, I think I am who I am and I'm okay with that'. My biggest frustration is that I can't get on and off the toilet by myself because my whole life revolves about people coming in and out to toilet me. So if I could do that, I mean, that would just be fabulous!

TECHNOLOGY AND IDENTITY

The positive attributes of technology identified by the participants contributed to an integral aspect of selfhood and bodily experience: the opportunity to engage more easily in social relationships. For most of the participants, technologies were valued for allowing them to tame the disorderly aspects of their bodies and thus to facilitate social integration. They drew an important distinction, however, between the technologies they considered more 'normalising' and others which they saw as marginalising or stigmatising. All the participants felt strongly that their disability should not come to define their identities. As Tom argued:

I don't want to be particularly conspicuous on account of my particular way of dealing with my disability or because of my disability for that matter. I really want to be known as yes, a person that has a disability but has a lot of attributes too. So I'd like to be known in context rather than just one part of me being known. Often the visible technology that I use attracts attention to that.

The notion of integration, thus, involved not only bodily functioning close to ideas of the norm, but also avoiding the use of technologies that overtly bespoke of a disability. The relative 'invisibility' or social acceptability of technologies was therefore important to people. For example, the people with visual disability discussed how they were treated when they used a guide dog compared with using a cane or an electronic sensor. They noted that when they used the dog, people tended to treat them in a more friendly and accepting manner. They suggested that the cane or ultrasound

sensor may serve to make them look more alienating and ‘different’ to others. As Margie put it:

A dog is far more suitable than using something like a mote sensor and a sonic pathfinder, for example, which are electronic aids that are either hand-held, or one actually sits on your head, like a head band with ear plugs and a big thing across the forehead and stuff. I really believe that something like that is not – well, it’s not that it’s not socially acceptable, it’s more from the point of view that it’s socially frightening to a lot of people, because it doesn’t look particularly attractive, it can cause a few reactions in some people. Whereas, for example, to walk around with a dog is completely and utterly socially acceptable. And I think with technologies, the more obtrusive it is, the more offensive it can become to some people.

Several people noted that using technologies designed specifically for people with their disability may produce a response from others that was highly stigmatising. Tom commented, for example, that people often made offensive assumptions about his intelligence when he was using a cane, but did not do so when he used a technology that was in general use:

I think it’s not so much the technology as what the technology refers back to the user of the technology. That is, as soon as you pull out a long white cane, then people start making assumptions, sometimes right, sometimes wrong, about your level of vision, about your level of intelligence or sorts of things like that, sort of indirect associations that are formed. And you know, I think the best example is something where that does not happen, like the little [electronic] business memo that I use. I have to explain to people, ‘Look I’ll just take a note of this, I’m going to speak into my business memo’. People think ‘Gee, that’s really cool’, you know because anyone can use that, it’s not specially related to people with disability.

The wheelchair was often raised as a particular exemplar of how technologies may mark people out as ‘different’. As Jenny, who is 30 and has paraplegia pointed out, ‘a wheelchair is a signifier of disability’. She argued that the focus in general discourses on ‘helping’ people with disabilities with technologies is offensive. In her own case, as someone who uses a wheelchair for mobility, she was offended by:

all those soppy [women's magazine] articles that have these brave profiles – 'They told me I'd never walk again and I walked out of that hospital'. Yeah right! You could've been doing something useful, get yourself a decent wheelchair, go and learn how to use it and then go and do something useful!

Jenny criticised the idea put forward in such popular accounts that using a wheelchair is the worst thing that could happen to someone, the end of a useful and happy life. Such accounts, she observed, underline the position of people with disabilities as 'a lower human being'.

It was observed by other wheelchair-using participants that this technology tended to detract attention from the identity and individuality of the person using it. Jo was particularly vehement on this point, noting that:

The wheelchair is the topic of discussion whenever you get into a lift – how well it turns, can you reverse, do you have license, you know, all of those things. And sometimes you'd like to chuck it in the bin, I guess, just to say 'Excuse me, but it's about me!' You know, so it takes the focus from me.

Ian, however, could see both positive and negative aspects to using a wheelchair. He noted that his wheelchair both drew attention to his 'difference' but also enabled him to achieve a greater degree of mobility and interact with others:

I don't want people to feel sorry for me, that's one. And two, the chair just screams out 'Look at me!' and you get like crowds of people just staring at this chair ... [On the other hand], if I didn't use the wheelchair I'd be laid up in bed 24 hours, 7 days a week. So the advantage is yes, I can get around, it's a means of transport and yes, it's a little bit of quality of life.

Several people with cerebral palsy identified a particular technology that they found even more intrusive than a wheelchair – the communication board (involving using a pointer to point to letters consecutively to spell out words rather than speaking them) or its electronic version. Ron argued that a wheelchair was more socially acceptable than using an electronic communicator or computer to communicate with people face to face:

I can go into a party [in a wheelchair] and I'm Ron, but if I took a computer in there or a communicator I'd be viewed as Ron and the computer, or Ron and the communicator.

[...]

The technologies Kate uses, she said, must address 'what I need them for but also they have to fit into my view of myself and the way that I want to present myself to the community'.

Several participants emphasised the point that where once using computers to communicate or perform work tasks might have singled out people with disabilities as 'different', this is no longer necessarily the case because these technologies are now used extensively in the workplace and at academic institutions. Tom commented, for example, that:

Certainly in terms of computerised technology, yes [it helps me fit in]. Although I'm obviously using it a different way, it makes me feel more like other people because everybody in my current workplace [a government department] uses PCs, it's a fairly major part of their work.

Further, for a majority of the participants, computer technologies were seen to facilitate communication. People could have a choice whether or not they wished others to know about their disability and thus were able to avoid, to some extent, the discriminatory attitudes they otherwise encountered. As Ann, 35, who has cerebral palsy put it:

Because they can't see you, they don't know how disabled you are, they don't even know how you are accessing the keyboard. They're talking with you by your computer and disability doesn't even come into it because they speak to you like an able-bodied person. And especially when you have a speech disability, people on the outside think that because we speak slowly that we think slow and we get patronised all the time. But on the bulletin board I never get patronised, because they don't really know if you have a disability unless you tell them that you have got a disability.

[...]

CONCLUSION

It was clear from this preliminary study that people with disabilities may attach great importance to some of the technologies they use. The participants identified and strongly affirmed a number of attributes offered by technology – communication with others, mobility, physical safety, personal autonomy, control, independence, competence, confidence, the ability to better engage in social relationships, the workforce and participation in wider community. These attributes are key components of their sense of self and wellbeing.

[...]

Technologies were conceptualised in two dominant ways by our participants: as tools assisting bodily function and as contributing to the body/self as it is experienced and presented to others. Some technologies allowed the participants to present themselves in ways which fitted with dominant values associated with functioning, capable individuals who need little help from others. The opportunity to construct and present this ideal self, contra to the meanings of passivity and helplessness that are commonly associated with disability, is clearly a choice that was of great importance to the people we interviewed. Such technologies, therefore, were incorporated unproblematically into their notions of self and body. In contrast, those technologies that served to underline the participants' status as 'disabled', to single them out as 'deviant bodies', tended to be greeted with greater ambivalence by the interviewees. Some people rejected these technologies outright, seeing them as barriers to presenting their preferred self even though they may have enhanced bodily capacities. These technologies were not incorporated, but rather were conceptually positioned as 'other' to oneself.[...]

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