



Technology, selfhood and physical disability

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Abstract

Much has been written in recent times of the interface between technologies and the human body. The vast majority of this literature, however, focuses on a body that is assumed to be free of physical disability. This article seeks to address this lacuna by presenting findings from an exploratory study using in-depth interviews with fifteen people with physical disabilities living in the Australian city of Adelaide. 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 data showed that the interviewees identified several technologies that they used as highly beneficial to allowing them to transcend some aspects of their disabilities. However, the interviewees also identified significant negative aspects to the use of some technologies. They noted that such technologies could serve to mark out people with disabilities as ‘different’ or ‘lacking’, acting as a barrier to the achievement and presentation of their preferred body/self. © 2000 Elsevier Science Ltd. All rights reserved.

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Introduction

Much has been written in recent years about the sociocultural dimensions of the interface between the human fleshly body and technologies (for example Haraway, 1991; Penley and Ross, 1991; Gray, 1995; Halberstam and Livingston, 1995). In particular the introduction of new computer technologies such as the personal computer, virtual reality and the Internet has incited interest in how the ontology of bodily experience and selfhood are altered via the human/machine

interface. This literature tends to take a highly relativist position on the body, seeing it as highly malleable by the discourses and apparatuses of technology. It is also often utopian in its visions of how the body might be enhanced by technology.

The vast bulk of this writing, while offering some intriguing insights and visions on new ways of conceptualizing bodies, has had little to offer on the ways in which different types of bodies — including those that do not conform to dominant notions of ‘normality’ — may relate to technologies. The model of the human body as it is presented in such texts is typically assumed to be free of illness or physical disability. As Balsalmo has noted, in the discourses of technoculture, “Techno-bodies are healthy, enhanced and fully functional” (Balsalmo, 1995, 216). Technologies are con-

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ceptualized as adding to the capabilities of such a body, enhancing its potential beyond 'normal' functioning. Yet it could be argued that people with illnesses or disabilities¹ have much more potentially to gain from technological enhancements of bodily capacities than do others.

This article 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 (for example 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 (for example, Oliver, 1990). The two perspectives are inter-

connected, because material disadvantage is in large part influenced by the tenor of sociocultural representations of and responses to impairment.

Further theoretical insights that relate more specifically to the interaction of bodies and selves with technologies are generated by the literature on the sociocultural meanings of technologies. In this literature, technologies are viewed as phenomena that both produce social relations and are themselves constituted in and through social relations. The form and function of technologies, themselves shaped by their human developers, serve to direct human action, embodiment and thought in certain ways (Callon, 1991; Woolgar, 1991; Latour, 1992). As Idhe (1990) puts it, technologies 'texture' their own use as well as their users' perceptions of reality and the social world. The use of technologies is not a purely individualized activity: it always takes place in a sociocultural context that both shapes the meanings of technological artefacts and places limits on the extent to which such meanings can be transformed by users.

Any human body using any form of technology may be interpreted as in some way adopting prostheses to enhance its capacities. Nearly everyone in contemporary western societies has developed a close dependency on technologies to function in everyday life, such as using spectacles to see clearly or a car to achieve greater mobility. As this suggests, the category of 'disability' is not fixed, but rather is fluid and shifting, a continuum rather than a dichotomy (Davis, 1995; Shildrick and Price, 1996). Nonetheless, 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 stigmatization and marginalization (Oliver, 1990; Hevey, 1992; Davis, 1995; 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" (1995, 12).

From a constructionist perspective, while the person with a disability may not feel ill or be in pain, her or his body is coded as a dysfunctional body. It culturally exists as a transgression, a body that straddles boundaries and therefore is anomalous, 'matter out of place' and threatening to the social order (Douglas, 1966; Thomson, 1997). According to Thomson, "the disabled figure operates as the vividly embodied, stigmatized other whose social role is to symbolically free the privileged, idealized figure of the... self from the vagaries and vulnerabilities of embodiment" (1997, 7). In a society in which people with physical disabilities are still

¹ The language that is used to denote disability or impairment has been the subject of much debate among commentators in disability studies. It is common in this literature to argue that 'impairment' should be the term used to denote loss of a body part or defective physical functioning, while 'disability' refers to the sociocultural and economic disadvantage, oppression and exclusion suffered by people who have impairments (for example, Oliver, 1990, 11). This distinction, however, fails to take into account that the meanings of impairment are also socially constructed. As Hughes and Paterson contend, "impairment is more than a medical issue. It is both an experience and a discursive construction" (1997, 329). In a further distinction, many writers prefer to use the term 'person or people with disabilities' rather than 'disabled person/people' to suggest that people's subjectivity should not be framed by their disability. Others, however, disagree, arguing that this choice avoids the fact that disability is unavoidably 'an essential part of the self' and that it is therefore 'nonsensical to talk about the person and the disability separately' (Oliver, 1990, xiii). We have chosen in this article to refer to 'disability' in relation to the physical loss of function suffered by our interviewees and also to use the term 'person with disabilities', as these terms were preferred and used by most of our participants when describing themselves.

commonly represented and treated as lacking, as 'deviant' or 'grotesque' bodies expected to conform to social structures and expectations of mainstream society (Shakespeare, 1994; 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 marginalization.

People with disabilities have historically been excluded from full participation in society and active citizenship (Abberley, 1987; 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, 1998a, 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; 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 'normalization' of impairment, or as allowing people to 'overcome' their impairments, an approach which Roulstone (1998a) characterizes as the 'deficit model' of technological aid.

Some writers in disability studies have used their own experiences to reflect on the value and politics of the technologies offered people with disabilities. French (1993, 46) argues, for example, that "Technological aids are a mixed blessing". She sees her word-processor, adapted to enlarge print on the screen to help with her visual disability, as a 'marvellous machine' and goes on to add that "I would not be without it". Yet she also sees such aids as potential burdens, because they sometimes give others the impression that

"the disabled person is managing perfectly well and requires no assistance" (1993, 46). French questions the notion that independence via technological aid is necessarily beneficial, arguing that in using such aids the person with disabilities may become isolated through the illusion of independence. Further, technologies may reinforce the notion that disability is solely a problem of individuals that can be dealt with by the use of a prescribed technology, drawing attention away from the political dimensions of disability. Technologies may thus be described as 'double-edged' in terms of what they might offer people with disabilities (Oliver, 1990, 126).

Issues around the use of technologies for people with disabilities, therefore, are potentially fraught with controversy. Yet, apart from the autobiographical accounts given by some people with disabilities, there is little recent literature that looks at the role played by technologies in everyday life for people with disabilities. Indeed some critics have argued that disability studies has tended towards a view that in some ways denies the phenomenological physicality of the body in its efforts to emphasize the social constructedness of disability. It is contended that this literature has thus presented people with disabilities as victims rather than as active subjects (Hughes and Paterson, 1997; Watson, 1998). These critics subsequently call for more research into the lived experience of disability.

Few studies have sought to ask people with disabilities about their use of and attitudes towards technologies. Most accounts of technology and disability have proceeded from a 'top-down' rehabilitation perspective which tends not to position technologies in their political or phenomenological contexts. Further, they often adopt the 'deficit model' approach to how technologies might assist people with disabilities (Roulstone, 1998a, 112). One important exception is a British study conducted by Roulstone (1998a, b) in the early 1990s, in which he interviewed 30 people with a range of disabilities about the role of new technology in their employment and search for employment. The findings suggested that the participants found that new technologies served in many ways to enhance their opportunities for employment. These technologies removed important barriers by allowing people to work in one central work-station, reducing the physical demands of the work place and therefore equalizing the work environment, facilitating communication and allowing their work to be judged on its own merits.

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 computerized 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 disability². This first phase sought to establish a general understanding and identification of some major issues around disability and technology, including the use of technology outside the paid employment sphere. This phase is to be followed by a more specific second phase focusing in detail on people with disabilities' engagement with new computerized communication technologies, both in the workplace and at home.

Initial funding allowed for a total of 15 people with disabilities to be interviewed in 1998 for the first phase, using a semi-structured schedule. Recruitment was through a non-representative convenience sampling strategy. The participants were recruited through the second author's contacts with various community organisations and agencies for people with disabilities located in Adelaide, who asked for volunteers. 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 small number of participants and the method of their recruitment, means that the data are not generalizable to the wider population of people sharing these disabilities, still less to people with disabilities in general. Nonetheless, as an inductive study rather than one seeking to test hypotheses, the data collected allowed the identification of factors which enhanced and inhibited the engagement of people with disabilities with technology.

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 techno-

logical 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.

All interviews were carried out by a research assistant and were audiotaped and transcribed. The transcripts were then analysed for recurring patterns, discourses and themes across the participants' accounts. The data were analyzed bearing in mind the following research questions: How did the participants conceptualize technology? How did they use it? What was the relationship between their particular disability and the types of technology they preferred to use? How did notions of self and embodiment interact with the conceptualization and use of technology? What are the facilitators and barriers to the use of technology? For the purposes of the discussion here, four major aspects of the participants' engagement with technology are elaborated upon below: the types of technology used; the benefits of technology; technology and identity; and problems with access to technology. All names used below to identify the study participants are pseudonyms.

Types of technology used

In the interviews, the participants were first asked to define what they meant by the word 'technology'. The general thrust of participants' replies to this question rested on the notion that technologies assisted human action in some way. Tom, who is 46 years old and has a visual disability, put it this way:

[Technologies are] any tools which humans use to do things either more easily or to do things that were not formerly possible without that tool. It could be really simple or really complicated, like anything from a computer to a screwdriver — anything which I suppose enables us to do something that with our fingers and arms and hands and eyes we just can't do. Glasses, hearing aids, all of those sorts of things.

The notion of technology as a 'tool' was raised by most participants in relation to how it might help them in dealing with their disability. Peter, a 35-year-old with quadriplegia, elaborated on this conceptualization, commenting that:

Technology for me is totally as a tool, I always used technology as a tool.... After my accident I looked at ways that I could make things work for me. That was before computers, so it was like a typewriter for writing things.... As computers came in, I came to think I could get around with compu-

² This research was funded by an Australian Research Council small grant awarded to the authors by the University of South Australia.

ters and so then got into those. So it was very much about what technology can do for me and help me with my disability. I think that if I wasn't disabled I probably wouldn't be using the level of technology that I am now.

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.

Few participants mentioned medicinal or therapeutic devices in their list of the technologies they used. The exceptions were two men with paralysis, one of whom described the machine he used to electronically stimulate his muscles to keep them in good condition. The other said that he was considering the use of a pump permanently inserted in his body to distribute doses of a drug to control muscle spasms. That most of the participants did not tend to mention therapeutic devices as technologies suggests again that their major conceptualization of technology was as a tool that helped them function in their everyday lives to perform mundane tasks.

Several participants emphasized the point that the technologies they found particularly useful had not been developed with people with disabilities in mind.

For example, Sam, a 36-year-old man with quadriplegia, mentioned air conditioning as very important to him as a way of maintaining an even body temperature:

Air conditioning units may be pretty commonplace for most people, but depending on how the body requires heat and things like that, it's an important part of the necessity really that I'm in.

Sam also discussed the importance of the electronic key pad that gave him access to his house in lieu of using a key. This was a technology that again had not been developed specifically for people with disabilities, but had been adapted for his use. Sam noted that:

I find that there are not a lot of, or I haven't come across a lot of things done or made specifically for the disabled. I think a lot of them are spin-offs from areas other than that, that have been adapted or certainly used by disabled people that were never originally intended for that use.

As a result, he observed, while such technologies were useful in some ways, he found them often difficult to use because of his disability:

My air conditioning key pad, for example, is very difficult for me to use. It's a push button — not so much a button but control pad — the buttons are hard to push. And with my level of disability, I don't have hand control, so I've got to actually push with my elbow. So it's a bit fiddly, it's actually quite hard to push even for an able-bodied person. The unit that was put in was not looked at from the point of view of myself using it, even though I was the one who had it put in. The contractors hadn't looked at that unit specifically for my use, so the technology is only barely useable by myself. It's quite difficult for me to use, it's taken me a long time to get to a stage where I can use it and even now it's still quite frustrating to use.

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 quadri-

plegia, 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 emphasize 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 that give a sense of control and autonomy were inextricably interlinked with notions of independence for the participants. Peter argued, for example:

I mean, independence is a funny thing, but it’s just things that other people take for granted.... It’s a basic need, like a need for shelter and food and security and protection and things which we all have as human beings. There’s things we all do, basic things, it’s one of those basic fundamental things that we all do, to be able to write, to be able to communicate, to be able to do something, really. For instance, at home I can’t, I may not be able to turn a light switch on in my lounge room, but I can go to my work room where I’ve got my computer set up and without any assistance at all do something. Now to me that’s something I can do independently, I don’t need anybody to help me to do it.

Margie, aged 24, who has a visual disability, also gave the example of a specific technology — in her case, a water leveller — and how it gave her a sense of competence and autonomy because it meant that she could do things for herself without help:

I love my water leveller, I really like that because it means that I can function competently without putting myself in danger or I don’t put myself at risk of an injury which makes me feel real good. And that means I can do it myself, no one has to do it for me, like when making drinks and stuff.

Margie went on to talk about the ‘sense of freedom’ she felt she gained using such technologies. She also felt that these technologies helped to connect to the ‘real world’ rather than being isolated:

It gives you a sense of, you’re actually a real person and you actually have a brain yourself. It’s a sense of reality, it gives you a sense that you’re living in the real world. So it gives you that sense of first freedom from your isolation.

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!

Tom talked about the two most important things that technology helped him with — mobility and communication:

Since being totally blind I feel much more traffic vulnerable, not so much getting lost or anything, just getting run over. And I have a secondary fear of actually causing injury to another pedestrian when I’m run down. So the mobility stuff [using an ultrasound sensor] is highly valued. The communication stuff, my little [electronic] business memo which means I don’t have to carry a hundred thoughts in my head at once and a computer which enables me to organise and communicate or receive other people’s thoughts, are also highly valued for that purpose.

Bill, a 37-year-old with quadriplegia, said that he thought mobile phones were particularly important, offering safety and security for those with limited mobility:

If I, for example, break down in my car in the street, walking a kilometre of two to the local service station is usually a big chore and I think that could be quite dangerous. Personally and physically, even if I just get there intact, the exertion made would be quite excessive. And so having that phone allows me to contact road services quickly.

Computer technologies allowed many people to engage in communication with others, including those who had similar disabilities to themselves. Kate, 27, who has cerebral palsy, accesses an interactive bulletin

board for people with disabilities through her computer. She sees it as vital in allowing her to share ideas and resources and have contact with people in a similar situation:

It's an opportunity to meet other people and it's an opportunity I wouldn't have without it, because my disability makes it awkward to meet people and the bulletin board is another avenue to meet people.

When talking about the technologies they used, several participants evoked the idea of the pleasure of mastery, the joy of accomplishment. In dealing with a sociocultural context in which they tend to be positioned as 'helpless', 'passive' and 'dependent', achieving this mastery and competence is vitally important to their sense of self. Jack, a 40-year-old with hemiplegia, described the benefits of using a computer in this way:

Well, I feel it is good in a lot of ways because of being able to correct things like in an easier manner, to be able to go back and undo things when, you know, you've made mistakes straight away or it comes up when you've made it and shows the spell check or whatever. That is, I find that really good.... I suppose it makes me feel good because, you know, you're making it right, just letting me know that within myself I'm doing it for someone else and I've got it right. You've achieved a sense of achievement.

For many of the participants, their competence in computer technology also enabled them to engage in higher education and compete in the job market, providing both financial and personal advantages. Indeed, it was commented by several people that were able to demonstrate a proficiency that exceeded that of many people and this can be a source of great satisfaction. As Ian, a 36-year-old with paraplegia, observed:

With a computer you could come up with a terrific computer program, make a fortune and it doesn't matter if you're in a wheelchair or not!

Sam also made the point that being able to demonstrate proficiency was important in presenting the self as knowledgeable and capable:

I think [proficiency in computer use] has a social significance in the way that you deal with other people and I think that rubs off. If other people see that you're competently doing and confident in what you're doing, then I think they treat you differently.

The opportunity to support oneself and to engage with others regularly are features that were highly

prized by those using computer technologies in employment. Jo observed that her job makes her feel less of a "burden on society" because it "gives me money, so financial independence, it gives me social contacts, gives me status in society and I guess they're the main things". Kate talked about how she used a computer to engage in further education, allowing her to refrain to be an advocate for people with disabilities:

It has been important because with my studies I've been able to change my career path. I was a desktop publisher and I found that wasn't satisfying and now I'm in the area of advocacy and it's much more satisfying.

In terms of personal development, this career change had made her feel much more 'powerful':

I've gained a lot professionally but I've gained even more personally. It's made me evaluate my attitudes towards people, towards myself and I've gained a lot more confidence.

Ron, 28, who has cerebral palsy, works as a computer programmer and consultant. He said that without the computer he wouldn't be able to keep himself gainfully employed or keep his 'mind ticking' or compete successfully with other businesses. Nor would he be able to communicate with people: "One day I was without the computer for a whole week and I nearly went mad!"

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 'normalizing' and others which they saw as marginalizing or stigmatizing. 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 stigmatizing. 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 criticized 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.

Kate also commented that she has trenchantly avoided using communication boards, even though her illness has resulted in a speech impediment that is difficult for some people to understand at first. She asserted that rather than forcing her to use a communication board, people should make the effort to understand her. Using such a device, she said, would slow down communication, make her feel far more conspicuous and encourage discriminatory attitudes:

There are already assumptions that because I'm in a wheelchair and because I look different that I'm not as smart as most people — using communication boards would add to that.

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 emphasized 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 computerized 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 patronized all the time. But on the bulletin board I never get patronized, because they don't really know if you have a disability unless you tell them that you have got a disability.

Problems with access

The development and marketing of new technologies are bound to an economy privileging profit rather than an economy of need. These technologies, therefore, are far more accessible to the socioeconomically privileged in society. This was an issue raised by most of the participants when discussing the use of technology. Several of the participants noted that they faced the continual problem of being left behind because of lack of access to newer equipment or training. There are few training programs on mainstream technologies that can accommodate the needs of people with disabilities and many do not have the financial resources to obtain new devices or upgrade their existing technologies. Tom says:

You know, there's Bill Gates and all the Microsoft stuff tears on into the future. I feel, I fear I'll always have this lag of them. There will be a new innovation which will become marketable, saturate the market and then there am I, depending on a few other technology buffs who've committed to social justice, I suppose, trying to catch up with it, under-resourced and under-powered. But we've done it, you know, more or less, but each time you jump one of those hurdles you wonder ‘Is the next one going to be too high?’.

The cost of technologies can also be prohibitive for many people. Jo, who works as a social worker and advocate for people with disabilities, noted that:

I think that's a frustration for me, is that often I see things, for example, environmental controls where somebody with high quadriplegia and is stuck in bed could actually say ‘Lights on, lights off, television on, change channel’. But they're \$9000 and out of the budget that we hold. There's no way we have \$9000 to fund someone to be that independent, which means they have to have somebody there full-time to put lights on and lights off and that sort of thing. So that's my frustration, I think.

Peter claims that new developments in technologies, leading to the costly need to upgrade equipment, often

have a greater impact for those with disabilities. As an example, Peter talked of a family who may have a computer that costs \$3000 and use only 5% of its capacity for relatively trivial activities such as playing games or wordprocessing. He argued that in contrast, whether people with disabilities can afford a computer or not may make a great difference in their lives:

[A computer] for a person with a disability might mean the difference between communicating and not communicating. You know, somebody who has difficulty in speaking can type things out and then communicate that way and it's a huge difference. Now to me, there's an injustice somewhere and there's not a recognition that for people with disabilities it is more need than want. The benefit there is it can be really life-changing, not just a help or something, an aside to your life.

Dependence on others for funding expensive technologies may mean that people with disabilities are placed in an invidious situation of having to accept technologies that they would not have chosen themselves. For example, Jenny recounted how she was pressured by a funding body to accept a less expensive wheelchair than the one she preferred and knew would be much easier to use.

The participants also pointed out that when breakdowns in technology occur, it can be difficult for some people with disabilities to deal with the problem. Margie gave the example of an experience when her mobile phone would not work. Her visual disability prevented her from reading the screen's display to identify the problem. She went on to argue that:

I suppose technology is wonderful, but it's not fool-proof and it's the foolproof part that really worries me. The fact that, you know, you could be working away on the computer and you completely lose your file or you could have to read something urgently and suddenly the scanner decides it doesn't want to work for you.

The issue of dependence on technologies worried other participants. Sam commented, for example, that:

Over reliance on them [worries me] and having a piece of technology that becomes essential, that doesn't work, or fails to work at some stage. For example the air conditioner, it doesn't work in my bedroom at the moment, it only happened last night. And I had to get on and get that fixed as soon as possible because the heating is most important for me and at the moment I don't have it in the bedroom, which with the cold weather coming up is

actually a problem. So I think that's just one thing that I've become reliant upon. I hate to think that that would suddenly disappear or that would fail to work or break. I've got an electric hoist, now if that broke down one day, then I wouldn't be able to get into or out of the bed.

Breakdown or failure of technology place the individual in a predicament: the feelings of autonomy, self-control, independence and normality that have been painstakingly achieved are challenged and disrupted. Jo described, for example, how finding herself in situations where she cannot properly use her wheelchair serves to relegate her back to a highly dependent status, one she found highly frustrating. Jo's words underline the ways in which enabling technologies in some contexts can be disabling in others. Use of her wheelchair, she said,

allows me to have equal status with people without disabilities when access for the technology is available. So in other words I get fairly frustrated if I get somewhere and there's not a ramp so that I can't use my technology to get into where I need to get into. So for me without my wheelchair, I become fully dependent, my status drops and I feel very burdensome.

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. However, what could almost be described as a 'love/hate' relationship was evident in the words many of the participants chose to discuss their feelings about the technologies they used. While they acknowledged the ways in which technologies assisted them, some technologies were actively disliked and resisted by the participants and many participants were acutely aware of their dependence upon other technologies, upon which they relied for everyday functioning and the presentation of a competent self.

As noted in the Introduction, all individuals in western societies interact with technologies in ways that texture their ideas of selfhood and ways of thinking about and using their bodies. This role of technologies

is represented in both utopian and dystopian ways in mainstream popular culture, suggesting a strong feeling of ambivalence about the ways in which technologies interact with humans (Lupton, 1995). Our findings suggest that for people with disabilities perhaps more so than for others, using technologies is risky. Technologies have the potential both to exacerbate disability and to enhance selfhood and embodied capacities.

Technologies were conceptualized 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.

It was also evident that, as other researchers have pointed out for some time now (for example Oliver, 1990; Roulstone, 1993), issues of access and resources remain vitally important for the use people with disabilities are able to make of technologies at the end of the millennium. As marginalized and often socioeconomically-disadvantaged members of society, people with disabilities are often deprived of the potential benefits that some technologies can offer them. Dependence on others for the funding or maintenance of technological equipment can eradicate or reduce many of its benefits. Our findings emphasize the importance of developing strategies for the adequate funding for appropriate equipment and continuing training in the use of technologies for people with disabilities.

Material factors, therefore, remain vital to the ways in which people with disabilities engage in technology. But the social construction of the meanings of technology and disability were also integral to the ways in which our participants talked about the impact of technologies on their lives. The negative meanings ascribed to such technologies as wheelchairs and communication boards, for example,

had a major effect on the participants' willingness to use such technologies and their feelings about how they were seen and treated by others. To use such technologies was to become entrapped within a framework of meaning that suggested helplessness, dependence and above all, difference, try as the participants might to resist or reframe these meanings. While the use of technologies designed for mainstream use may have avoided such stigmatization, material factors such as their design sometimes impeded the use people with disabilities could make of them.

Our study was limited in being small scale and exploratory and including people with a small range of disabilities. Further research is needed that can investigate facilitators and barriers to the use of the full range of technologies among a wider group of people with disabilities, including both material factors and those related to sociocultural meaning and which is sensitive to the ways in which the use of technology is inextricably interlinked with notions of selfhood and embodiment.

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