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THE TECHNOLOGICAL PROMISE: ENHANCING SOCIAL PARTICIPATION AND CITIZENSHIP FOR PEOPLE WITH DISABILITIES

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THE TECHNOLOGICAL PROMISE: ENHANCING SOCIAL PARTICIPATION AND CITIZENSHIP FOR PEOPLE WITH DISABILITIES

Wendy Seymour*

INTRODUCTION

The human body is frail and vulnerable. The fact that we possess a body renders us susceptible to disease, damage, pain, leakage and decay. While everyday tasks of body monitoring, maintenance and repair preoccupy us all, these tasks assume critical importance for people who live with permanent bodily damage (Seymour 1998: 17). The omnipresent risk of bodily disruption can dominate their lives. People with disabilities represent vivid examples of the frailty and vulnerability of embodiment, but the heightened risks that they must endure can greatly exacerbate the work involved in monitoring, maintaining and defending the body.

Technology offers the potential to free people with a disability from dependence and immersion in interventionist/therapeutic regimes of the past by enabling them to participate more fully in society and to take an active and creative role in their own embodiment. In order to facilitate this process, a clearer understanding of the perceptions of risk and apprehension which these people experience is essential. Determining the nature and extent of such fears will facilitate techno-cultural participation, and offer people with a disability a stronger sense of citizenship.

THE STUDY

The paper relates to a project begun in Adelaide, South Australia in 1998 that investigates disability, technology and risk. The study is directed at ascertaining issues of concern for people with disabilities in order to identify strategies to facilitate social participation. The project is focussed on two major themes: the tension between dependence and participation and, concurrently, the tension between risk and opportunity. Although these issues may be related to technological engagement more generally, negotiating the tensions may assume greatly increased significance for people who are already engaged in the ongoing task of body management. The additional work involved in initiating contact with technology, coupled with fear of disrupting the status quo, may heighten the difficulties and obscure the advantages for people with disabilities. It is within the context of risk that tensions between the body and technology are negotiated.

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The first stage of the research project aimed to establish a general understanding of the issues associated with technological engagement. In depth, face-to-face interviews were conducted with fifteen people with disabilities, using a semi-structured interview schedule. Ten men and five women were interviewed: seven participants are paralysed as a result of spinal injuries, four have cerebral palsy, one has a lower limb amputation and three of the participants are visually impaired. The ages of the participants range from nineteen to forty six.

The study interrogates four key areas associated with technological engagement. Firstly, the research is directed towards establishing the participants' understandings of the term 'technology' and their attitudes and reactions toward it. Investigating the possibility of a link between notions of technological suitability or acceptability and particular parts or functions of the body forms a second strand of the research. The third theme asks the participant to revisit and reflect upon his or her own experiences of technological engagement. The fourth strand of the research seeks to identify the barriers that may impede technological participation.

The purpose of this paper is to set the scene—to situate the study within a context of writings related to technology, risk, disability, embodiment, participation and citizenship. While subsequent papers will be dedicated to themes that emerge from the data collection, specific interview material and analysis will not be included in this paper.

PAST INFLUENCES

Ideas of risk and bodily competence are tied to particular forms of knowledge and notions of identity and human potentiality. The fears and anxieties which concern people at the end of the millennium are the product of particular ways of thought and bodily expression (Lupton 1995: 77–105). What comes to be seen as a risk is the result of sociocultural processes that are always political in their constitution, use and effect (Douglas and Wildavsky 1982; Petersen and Lupton 1996).

In the past the rehabilitation of people with bodies damaged by disease, injury or congenital trauma has been confined by particular perspectives and views of the world. To a large extent rehabilitation has taken place on the margins of medical and health care practice. Specific issues such as the long-term nature of many disabilities, the ongoing managements costs, the likelihood of ambiguous outcomes, the vulnerability of the consumer's body and the parsimony of public assistance have compounded aspects of the medical paradigm and effectively confined people with damaged bodies within the parameters of this perspective. While many people with damaged bodies may eschew medical care, few will escape the influence of this dominant paradigm on their lives.

'Personal tragedy theory' (Oliver 1990: 10) has also underpinned thinking about disability. The public discourse of disability focuses on individuals who achieve

success in endeavours that are valued in the able-bodied world. The extraordinary nature of their achievement is implicitly contrasted with the tragedy and loss which most people with damaged bodies must endure. The Paralympics, for example, celebrate achievements that equate with the dominant social values, obscuring other activities (Seymour 1997: 153). The games reinforce themes of private tragedy, bravery and the 'special' life of a person with a disability. The individualised locus of bodily loss and the medicalisation of the 'problem' continue to reinforce and enhance the diversionary power of this discourse (Oliver 1990: 60).

The development of a new 'rehabilitation industry' directed towards injured workers and the needs of the workplace has challenged some aspects of the medical model of rehabilitation. Not surprisingly, the new 'disability business' (Albrecht 1992: 27) has developed categories, expectations and views of the body which reflect its own commodified services (Albrecht 1992: 280) and strategically focused objectives. Though different in process and outcome, the rehabilitation industry offers little significant change in terms of the opportunities and satisfaction for people with damaged bodies.

These key perspectives have dominated the experience and culture of disability and the context of the rehabilitation enterprise. The prospects of people with disabilities have been confined by the assumptions underlying these formidable discourses. The lives of many people with long-term disabilities have been shaped by practices that have encouraged isolation and protection from risk. In a context dominated by medical thought, people with disabilities are 'sick' people who will never 'get well'. Past policies and practices, particularly those related to education, employment and housing, have encouraged isolation, segregation, dependence and overprotection, characteristics which epitomise the 'special life' of a person with a disability (Oliver 1990: 6).

Not only must these people manage their risk-laden body, but their socialisation and early experiences have deprived them of the very attributes most needed for this task: the confidence, learning and skills which come from experiencing, managing and mastering risks in the social world. While the dangers of living in and with a damaged body vastly increase the incidence of risk and the ongoing work involved in monitoring and managing these risks, the sequestering of experience (Giddens 1991: ch 5) leaves them ill-prepared to deal with risk. Poorly prepared to manage risks in their social environment, people with disabilities must daily manage the vagaries and dangers of their own leaky, frail and capricious bodies.

THEORETICAL THEMES

The study engages with the expanding body of work by writers such as Balsamo (1996), Dery (1996), Featherstone and Burrows (1995), Gray (1995), Haraway

(1991; 1995), Law (1991) and Wajcman (1991) that relates to the use and implications of technology. While these writers are not specifically concerned with disability, the universal and democratic nature of techno-culture must necessarily include people with a disability.

Drawing on the work of Giddens (1991), Beck (1992) and others, the research interrogates the issues of risk, and in particular the management of risk, as the means of addressing resistance to technology, and increasing the willingness of people with frail and damaged bodies to engaged with technology.

The theoretical work of Turner (1987; 1991; 1992; 1994; 1996) and Shilling (1993) related to embodiment also underpins this work. In the past, virtue, albeit limited, was afforded those people who bravely accepted the limitations of their bodies. This dispensation has all but disappeared in an era in which endless possibilities for bodily manipulation exist. 'Techno-bodies'—the interface between technology and the body—represent a dramatic challenge to our understanding of what a body is, and what a body can do. Although the concepts of 'embodiment' (Turner 1994: xi), 're-embodiment' and 'remaking the body' (Seymour 1998) derive from current theoretical debates in the sociology of the body, these concepts relate to key issues in the practice of rehabilitation in both the formal and informal sense of the term.

TECHNOLOGY

The term 'technology' includes applications as diverse as vacuum cleaners and virtual reality, prostheses and cyborgs (Gray et al 1995: 2). While we have gradually accommodated ourselves to accept a range of pharmacological and surgical interventions to remedy problems in sick or disordered bodies, we are now faced with techniques which can extend the body's capabilities far beyond the parameters of what we assumed was 'normal'. Although many people welcome the expansive opportunities, others have been left in the wake of technological developments.

Technology offers the potential to extend the functions and activities of the body, to supplement inadequate performance, enhance endurance and heighten experience and sensation. More importantly, technology may enable people with disabilities to transcend the confining nature of disability discourse and identify with and participate in global techno-culture. These developments promise to detach disability from its medical antecedents and from the managerial dimensions of the contemporary rehabilitation industry. By engaging with new technologies, people with damaged bodies may free themselves from the 'special' world of disability with its limited techniques and prospects and its restricted notions of participation, achievement and satisfaction.

PARTICIPATION

Many people with disabilities feel politically disenfranchised and alienated from processes that influence their lives. Direct participation in social and political life presumes able-bodiedness: it is predicated on sophisticated and well-honed skills of articulation, elocution, debate and quick repartee, underpinned by complex and extensive bodily synchronisation and representation. Particular verbal and bodily presentations are seen to characterise acceptable forms of political participation. Bodily posture, gesture and demeanour convey sincerity, confidence, altruism and responsibility. Coupled with restricted assumptions about political eligibility, such forms of participation alienate many people. It is not surprising that the voices of people with disabilities make little impact amidst the noise of competing participants in debates about social policy, political inclusivity and citizenship.

Implicit in the structures of representational democracy is the provision for a person or small group of people to represent or advocate on behalf of a much larger constituency of people, a situation which 'is always considerably less than perfect' (Campbell and Oliver 1996: 100). Spurred by the civil rights movement, the women's movement and an emerging disability consciousness, the disability movement arose, recognising that political representation by others could never serve the interests of people with disabilities (Campbell and Oliver 1996: 62). Predicated on the collective strength and active involvement of people with disabilities in their own affairs (Barton 1996: 158), the disability movement has had considerable success in challenging the structures that have oppressed people with disabilities. Citizenship, however, is broader than the politics and activism of the disability movement, critical though this is, and social movements inevitably develop their own structures of representation and advocacy. While advocacy will remain important for some people, in general this strategy can be seen as counterproductive to inclusivity and participation. The concept of citizenship involves the possibilities of incorporation and active participation of all people, both individually and collectively, in every aspect of their lives and the provision of means by which this can occur. Access to information is essential in order to exercise the rights and responsibilities of citizenship and to participate in the democratic process (Steele 1998: 163). It is not enough to simply 'be informed', people must be able to actively seek the information they need in order to make decisions and choices about their bodies and the social world in which they live.

Since direct involvement of people with disabilities in political life is difficult to achieve on the inequitable terms of the able-bodied world, participation in techno-culture promises broader engagement and participation. By augmenting or substituting particular bodily functions and by transcending time and place, technology facilitates entry and participation into previously inaccessible activities and domains. Partaking in techno-culture offers the means for people with disabilities to enhance selfhood, as well as to develop a stronger sense of

citizenship. It positions a person with a disability in the wide-open spaces and possibilities of the global world. The opportunity to break away from the expectations associated with domestic, family and community life may enable the exploration of relationships beyond those rooted in proximity and shared physical experiences. While this may operate at the level of electronic penfriendship, it may also present opportunities for 'entirely new notions of social action … [which] may begin to emerge and challenge existing social structures' (Loader 1998: 10). By bypassing aspects of the biological body, people may engage with others in a more auspicious virtual world. It provides both the means and the possibilities of engagement—the means to transcend the frail body, and the possibility of engaging in bodiless participation.

RISK

But we must not let ourselves be overwhelmed by optimism about the technological future.

The vulnerability of bodies made frail by disease or disability has been greatly exacerbated by the practices and policies of the past. Overprotection and learned dependence have 'left people alone with their bodies' (Shilling 1993: 167). Restricted and invalidised, people with disabilities have been disadvantaged in acquiring the knowledge and skills that are gained through participation in everyday interaction. While living in bodies that epitomise the prejudiced attitudes of others, people with disabilities have been immunised from experiencing the prejudice and bigotry endemic in social institutions and practices. Yet protection from such attitudes and practices inhibits the development of strategies to manage these common aspects of social life. Boldness and confidence are developed through involvement in social situations, the experience of which promotes the gradual development of strategies to control or manage such situations. Inexperience in managing the hurly burly of social life leaves people with disabilities even more vulnerable in negotiating the wild woods of techno-culture. Although people with disabilities may have much to gain by engaging with the technological revolution, fear of losing hard-won gains may inhibit experimentation. The experience and culture of disability, coupled with the daily reality of living in a frail and vulnerable body, may discourage participation of the very people who could be most helped by technological innovation.

It is not hard to see that the wide variety, availability, sophistication and marketing of technology in recent years may represent a threat to many people. At base, new technologies are commodities for sale. The material components of the technological revolution are merely consumer goods that are managed and manipulated like other market products. Rapid obsolescence increases sales, but the consequent need to retrain with each technological 'advance' is costly and exacerbates the fear involved in having to continually learn new skills.

In the global market place, information technology is not only the focus of 'hard-sell' international advertising companies, it is itself an auspicious site of self-promotion. By its function and nature, information technology is uniquely positioned to expand its influence and enterprise by stimulating needs, provoking desires and creating dependency on its own products and services. While the rewards of international communication and global economic markets are a powerful inducement for many people, the prospect of exposure may intimidate others. People with disabilities may retreat in the face of these formidable elements of the capitalist enterprise.

The disparity between the 'information-advantaged' and those people who are excluded from the benefits of the information technology revolution is an issue of great concern (Loader 1998: xv). Access to the technologies and the skills required to participate in electronic communication is unevenly distributed. There is no doubt that the electronic world is far from neutral and techno-culture is contested space. While the internet may be presented as a democratic arena, it is clear that the medium has been thoroughly colonised by commercial and corporate interests. Utopian accounts of borderless and uncommitted cyberspace obscure the reality that the information society shares many of the features of capitalism at the *fin de siècle*. The benefits of participation are directly related to the material conditions of those people who are well-positioned to initiate their entry into techno-culture. Class, race, age, gender and disability carry clear associations of disadvantage. Action and inaction on the part of different groups of people in society has played a vital role in the evolution and characteristics of technological applications. 'Information-advantaged' groups, for example, may deliberately and systematically exclude 'information-poor' groups from participation in the wider community (Loader 1998: 8). Impoverished by circumstances, disadvantage is compounded by the lack of access, understanding and information needed to compete in the information marketplace. Representation by others reproduces the very problems associated with medicine and other paternalisms in relation to people with disabilities in the past. Powerful professionals define what people with disabilities 'really want and need'. Yet delay, reluctance or inability to engage with technology diminishes opportunities to influence the course of the techno-future. The social, economic and political relations of capitalism have shaped technological development: the danger is that technology may dramatically heighten its inequalities.

Yet, while formidable, the risks and hazards associated with technological engagement should not daunt us. Though often painful and frustrating, successfully managing a difficult situation can bring its own reward. Confidence and self-empowerment are acquired by mastering difficult situations.

Writers such as Beck (1992) and Giddens (1991) see risk as an inevitable consequence of late scientific and industrial development, but they view risk in

optimistic terms. They consider that the risks associated with late modernity offer an opportunity for people to reposition themselves in relation to social structure. The repositioning enables people to reflect and question current practices and understandings (Beck 1992: 176), a process that may free them to pursue new directions and opportunities.

Giddens considers that managing risk is a way to actively 'colonise the future'. Through risk calculation and 'counterfactual thought', the unknown future is shaped into a new terrain, which, once established, lends itself to colonial invasion (Giddens 1991: 111). Although colonisation exposes people to new risks, as individual life chances are automatically linked to global risk environments (Giddens, 1991: 118), it also presents people with a range of hitherto unimaginable opportunities. Released from the certainties and continuities of the industrial epoch, a '[n]ew twilight of opportunities and hazards comes into existence' (Beck 1992: 15).

CONCLUSION

Technology offers broader ways of having and being a body. It enables both 'body-less' communication and the creation of 'multiple bodies'. It presents ways of 'hearing' and 'speaking' voices that may be silent because of physical loss or lack of power. It is both the means and the opportunity to transcend the limitations of the old model of disability identity and to engage in new realms of understanding. It lifts the body out of the context of individual illness, disability and disadvantage and relocates it within the broad ambit of contemporary society and citizenship.

However, both citizenship and social relationships involve reciprocal responsibilities, duties and obligations (Seymour 1998: 3). While it is clear that technology can enable participation and strengthen embodiment in significant ways, it may also increase susceptibility to a range of risks and dangers. It can unsettle vulnerable reality, intensify exclusion and marginality, and deepen disadvantage. Overprotection, segregation and years of dependence on professional help have left people with disabilities unprepared to manage the risks and unpredictabilities of techno-culture. When bodily compliance must be renegotiated each day, reluctance to experiment with technology is not hard to understand. The liberatory promise, no matter how enticing, must be set against the possibility of losing hard-won gains The possibility of disrupting a precarious bodily truce may simply be too much to jeopardise. Predicability, familiarity and a sense of stability may always be more reassuring than flirting with an unknown world, despite the putative rewards.

Yet the promise of technology is more than a siren's song: it cannot be ignored. Technology offers people with disabilities the opportunity to actively participate in society and to reposition themselves in relation to social structure. The expansion of spatial and personal boundaries can free people to reflect and question current

practices and understandings, releasing them to pursue new directions and opportunities. In providing the opportunity to escape the narrow dimensions of disability identity, technologies may enable people to create innovative relationships and identities. Technical familiarity and competence engenders confidence in the ability to manipulate and control the environment and diminishes reliance on others. Released from the vagaries of bodily unreliability and dependence, people with disabilities may explore hitherto unimaginable opportunities.

The risks and hazards of technological engagement are ominous and substantial, yet failure to address new technologies may be even more threatening. It will relegate people with disabilities to the isolation, dependence, overprotection and limited opportunities of the past. For people with disabilities, the techno-future does not simply beckon; it demands exploration and mastery.

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