

**Disabled People and Communication Systems
in the Twenty First Century**

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

This thesis is first and foremost about oppression - the oppression experienced in our society by those with particular impairments. It is also about technology - the new information and communication systems which have increasing primacy in today's world. Specifically it is about the ways in which the communication systems of a disablist society hold both opportunities and threats for disabled people and their organisations in the twenty first century, perhaps changing the boundaries of the disabled category. In drawing on literature from both the sociology of technology and disability studies, it contributes to two bodies of academic work. It is intended as a welcome palliative to the growing tendency towards speculative futurology that characterises both disciplines, since it places an empirical study at centre stage. It is unusual in that its main emphasis is on domestic usage of communication systems, not on their use in employment. The research participants were largely unwaged people, many of them in older age groups. The study gave participants the opportunity to describe their experiences and opinions of technological developments in the last throes of the twentieth century. Access to communications systems emerged as a major issue, with disabled people facing a variety of barriers to their beneficial use of technology. Concerns were voiced however about the provision of such systems constituting little more than a 'technical fix', cutting welfare costs, enforcing further segregation and distracting attention from the real source of disabled people's oppression. These findings highlight the increasing importance of more radical social transformation. The opportunities and threats presented by the utilisation of communication systems are examined through an analysis of their use-value - how they allow or disallow the satisfaction of basic unmet needs. In conclusion, various recommendations are proposed which will go some way towards making technology more accessible and appropriate for disabled people. It is however acknowledged that this will merely treat a symptom of their oppression, not eradicate the cause.

TABLE OF CONTENTS

List of abbreviations.....	x
List of tables.....	xii
CHAPTER ONE: INTRODUCTION.....	1
Disabled people in the twenty first century.....	2
Communication systems in the twenty first century	4
Organising for the twenty first century	6
General outline of the study	6
A note on terminology	14
CHAPTER TWO: DISABILITY, TECHNOLOGY AND SOCIETY.....	15
Locating 'disability' in the definitional bog.....	15
The medical model	15
A socio-medical definition	16
A disabled people's definition: The social model of disability.....	18
Commonality or difference? Internal critiques of the social model	19
Disability, ageism and multiple oppression.....	20
Techno-enthusiasm and models of disability	22
Disabled people and the sociology of technology.....	23
Technological determinism	23
The social shaping of technology	25
Beyond technological determinism and social shaping?.....	26
A historical materialist analysis	28
Impaired people and feudalism.....	29
The rise of capitalism, the rise of disability.....	29
A brave new world? Finkelstein's 'Phase 3'	32

The telephone: A historical perspective on access.....	33
Use-value or <i>useless</i> -value, True needs or false needs	35
Disabled people and technology: Liberation or oppression?	41
Medical technology	42
Rehabilitation technology: Science-fact or science-fiction?	43
Independence, dependence or interdependence?	45
Fix this! Disability and the 'technical fix'	47
Summary	49
 CHAPTER THREE: RESEARCHING DISABLED PEOPLE AND COMMUNICATION SYSTEMS.....	
Emancipatory research	51
Theoretical assumptions	52
Objectivity	53
Positive gain	54
Changing the relations of research production.....	56
Strategies	57
The study: Overview.....	58
The sampling frame.....	60
Resource centre users	60
City-on-Line (COL) participants	61
What about the workers?	62
Participant observation.....	63
The focus groups	65
Focus groups and disability research.....	65
Setting up the focus groups	67
Conducting the focus groups	69
The individual interviews.....	70
Setting up the interviews	71

Interview schedules	75
The influence of the disabled researcher.....	76
From particular to general	78
Summary	79
CHAPTER FOUR: CORPORATIONS AND TECHNOLOGICAL ACCESS	80
Market forces / disabling forces?	81
The privatisation of telecommunications	83
The motivations of privatized companies	85
Manifest functions: Altruism or oppression?	86
Latent functions: Disabled people as profit generators	88
Universal design: Rhetoric or reality?.....	90
Universal design or specialist design?.....	92
Universal design or stigmatisation?.....	95
Universal design and multiple impairment.....	98
Universal design and complexity	99
User involvement	103
Information provision.....	104
Summary	112
CHAPTER FIVE: ACCESS AND THE SOCIAL MODEL OF DISABILITY.....	114
'Let the world come to you': Communication systems and 'housebound' people	115
'What life d'you have if you don't go out?'	118
Looking at four walls: Barriers to leaving the house	119
Get your priorities right!	121
The technical fix revisited.....	122
Money's too tight to mention: Economic barriers	124
Giz a job! Access to employment.....	126

Access to benefits	128
Living beyond one's means: The additional costs of impairment	130
Computer provision	132
Education, education, education	135
Further education: Training courses	138
Teaching yourself and back up support.....	143
Twenty first century basket-weaving: Education for what?	146
Internalised oppression and self-confidence	147
Technology, disability and difference.....	149
Old and past IT? Disability, older age and technological access	149
Is IT a man's world? Disability, gender and technology	153
Not feeling up to IT: Impairment effects and technological access	154
Summary	155
CHAPTER SIX: AUTONOMOUS LIVING IN THE VIRTUAL COMMUNITY. 157	
Physical survival	157
Personal autonomy and 'independence'	159
Care in the virtual community?.....	162
Sending out an SOS: The telephone as a 'lifeline'	166
'Help! I need somebody': Community alarms	169
'Computer - lights!': Smart housing	175
Security and autonomy outside the home	179
'Public' telephones: A public disgrace	179
Mobile phones: Benefits.....	181
Mobile phones: Barriers	185
Summary	188
CHAPTER SEVEN: INFORMATION, CITIZENSHIP AND CONSUMPTION.. 190	
Shopping around for information.....	190

Information and citizenship.....	193
Information technology and inclusive citizenship	195
Hitching a ride on the information superhighway.....	197
'What I fancy at the time': General information	198
'What I really need to find information about': Specialist Information	199
Information overload? Finding the relevant information	202
Inconspicuous consumption? Disabled people and online shopping	204
Online shopping: Problems	209
Just browsing: Shopping as a leisure activity.....	214
Online shopping and the technical fix	215
Freedom of information: Regulation and accessibility	217
Summary	220
CHAPTER EIGHT: NETWORKING FOR CHANGE.....	221
Get a friend, get a life: The basic need for social contact.....	221
Disabled and older people and isolation	222
Mediated communication: Effective replacement or useful addition?.....	225
'It's good to talk: Telephones and affiliation	227
Video conferencing	231
Computer mediated communication	234
Meeting in the virtual community.....	237
'Nobody knows you're a dog': Identity and passing	242
'Wow - I've got a voice!	246
Disabled people and e-activism	251
Summary	257
CHAPTER NINE: TOWARD A BRAVE NEW WORLD?.....	259
Summary of findings.....	259

Discussion	263
Recommendations	265
The limits of reform	266
BIBLIOGRAPHY	269

LIST OF ABBREVIATIONS

AARP	American Association of Retired Persons
ADAIP	Alliance for Disability Advice and Information Providers
ANT	Actor-Network Theory
BCODP	British Council of Disabled People
BDA	British Deaf Association
BSL	British Sign Language
BT	British Telecommunications plc
CMC	Computer Mediated Communication
COL	City-on-Line
CSDPA	Chronically Sick and Disabled Person's Act
DAA	Disability Awareness in Action
DAN	Disability Action Network
DCODP	Derbyshire Coalition of Disabled People
DIEL	Advisory Committee on Telecommunications for Disabled and Elderly People
DIG	Disablement Income Group
DLA	Disability Living Allowance
DOS	Disk Operating System
DPI	Disabled People's International
DTI	Department of Trade and Industry
ESRC	Economic and Social Research Council
FG	Focus Group
GMCDP	Greater Manchester Coalition of Disabled People
GPO	General Post Office
GPS	Global Positioning System
ICIDH	International Classification of Impairment, Disability and Handicap

IBM	International Business Machines
ICT	Information and communication technology
IT	Information technology
MS	Multiple Sclerosis
MUD	Multi-User Domain
NDIP	National Disability Information Project
OFTEL	Office of Telecommunications
OPCS	Office of Population, Censuses and Surveys
OT	Occupational Therapist
PC	Personal Computer
POSSUM	Patient Operated Selector Mechanism
RNIB	Royal National Institute for the Blind
SPOD	Association to Aid the Sexual and Personal Relationships of People with a Disability
TIDE	Technology Initiative for Disabled and Elderly People
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UMTS	Universal Mobile Telecommunications System
UPIAS	Union of Physically Impaired against Segregation
VW	Voluntary Worker
WAP	Wireless Application Protocol
WB	World Bank
WHO	World Health Organisation
WIPO	World Intellectual Property Organization
WTO	World Trade Organisation
WWW	World Wide Web

LIST OF TABLES

Figure 1: Focus groups69

Figure 2: Interview participants73

CHAPTER ONE: INTRODUCTION

This is a thesis about what is and what might be. It is a thesis about all our futures. What kind of world do we wish to inhabit in the twenty first century? What kind of world do we want for our children, and our children's children? The world we currently inhabit is not an equitable one. Countless millions are consigned to the margins nominally because of their biology or geography. The twenty first century could see increasing polarisation between the haves and have-nots. Alternatively, it could herald a new time of plenty where the oppressed people of the world break free of their chains. The future is not cast in stone. The new millennium will be what we make it.

How then to contemplate what is happening in the twenty first century? The focus here will be on one group of the have-nots - disabled people - those people with impairments who are currently excluded because of the way that society is organised. Specifically, it will examine disabled people's relationship with the new communication technologies that are increasingly said to be recasting all our futures. Will they, as some predict, be the key to our liberation? Is it possible that they could further marginalise us? Whilst I cannot promise answers to these questions, I hope to make a meaningful contribution to debates both within disability studies and the sociology of technology: disciplines that could learn much from each other. The area of study will now be briefly introduced, and an outline of subsequent chapters provided.

DISABLED PEOPLE IN THE TWENTY FIRST CENTURY

At present, institutional discrimination against disabled people is very deeply ingrained, so that they face a multitude of barriers to their full participation in society (Barnes 1991). It has been noted that:

on nearly every indicator of participation in mainstream life disabled people come out very badly: for example on employment statistics, income levels, suitable housing and access to public transport, buildings, information (newspapers, radio and television) and leisure facilities. (Finkelstein 1993: 11)

In addition, social provision for disabled people has been much criticised for reinforcing their dependency, and it seems that many disabled people lead very lonely and isolated lives (Barnes 1990). Disability then is a form of social oppression akin to racism and sexism (Abberley 1987; UPIAS 1976).

The disabled population is not a homogeneous one. It consists of people with a wide variety of impairments, and is intercut by a number of other forms of structural disadvantage. Whilst this thesis does not set out to create hierarchies, by singling out individual disabled people as more or less oppressed than others, it recognises that disablism cannot be confronted in isolation (Oliver 1996a). Any study of disabled people inevitably exposes unpalatable truths about society, the same society which disadvantages all oppressed people. It makes sense then to transform that society so that it includes all its citizens. As Colin Barnes suggests:

the politics of disablement is about far more than disabled people; it is about challenging oppression in all its forms... Like racism, sexism, heterosexism and all other forms of oppression, it is a human creation. It is impossible, therefore, to confront one type of oppression without confronting them all and, of course, the cultural values that created and sustain them. (in Campbell and Oliver 1996: xii)

In the 1980s, government statistics suggested that 6.5 million people in the UK were disabled (Martin *et al.* 1988). More recent data suggests that 40% of adults in this country have a 'long standing illness or disability' (CSO 1996). There are currently said to be around 50 million disabled people in the European Community

(Daunt 1991) and 500 million worldwide (DPI 1992). It seems that these figures are set to escalate dramatically as we move into the twenty-first century. Advances in living standards and medical technology are producing ever-longer life expectancies, so that the proportion of older people in the Western population is constantly rising. There is a marked correlation between disability and ageing with around 60% of those over 75 years old having at least one impairment (Martin *et al.* 1988). Furthermore, there are thought to be around 3.6 million disabled women to 2.5 million disabled men. These figures also vary considerably according to age group - there is a lower incidence of impairment in girls than in boys to around age 15, then from age 75, over 63% of women are disabled, compared to around 53% of men (Martin *et al.* 1988). Hence the majority of disabled people also face ageist and / or sexist oppression.

The escalating proportion of older and disabled people in the population has led to ageist concerns about the welfare state's ability to cope with the anticipated demographic time-bomb (Arber and Ginn 1991). This 'apocalyptic demography' assumes that not only will people live longer, they will also live sicker, thus placing an increased burden on younger, relatively healthy workers (Robertson 1997: 426). Demographic change is increasingly regarded as a cause for concern and is considered 'central to considering the future of policy on disability' (Christie and Mensah-Coker 1999: 25).

Despite claims that the 'political will to allocate resources' is far more crucial than any demographic trends (Arber and Ginn 1991: 12), a simple solution is increasingly suggested to the assumed problem of escalating 'care' costs - technology (Evandrou 1998; Taipale 1993). 'Care' is not however the only assumed use-value of technology for the expanding 'greying' population. Heinz Wolff (1983: 46) for example is optimistic that older people will be able to compensate for their 'failing physical and sensory powers' with the help of consumer products or 'tools for living'. These products will 'do what evolution has failed to do, which is to adapt us to becoming old'. He further elaborates on his vision of the future, by suggesting that older people will form an affluent and powerful group of consumers, and thus stimulate industry to produce the tools they require. This will also he claims, have benefits for younger

disabled people. However, contrary to Wolff's vision, many older people and disabled people are not sufficiently affluent, and technology has as yet done little to improve the problems of loneliness and social isolation that many face. It is even suggested that their isolation may be getting worse (Harbert 1997a). The technology now at our disposal is extraordinary however, and some disabled people are finding ways to use it to their advantage. As we will see, perhaps the most innovative developments have been, and will continue to be, in the area of communication systems:

COMMUNICATION SYSTEMS IN THE TWENTY FIRST CENTURY

Massive developments are taking place in the fields of information and communication technology (ICT). The telephone has developed at an unprecedented speed, as has the computer, and the boundaries between telecommunications and information technology are becoming increasingly blurred. Even experts in the field have difficulty keeping up to date with new developments (Lindstrom and McEwan 1991). Manuel Castells for example begins his trilogy *The Information Age: Economy, Society and Culture* (1996, 1997, 2000) with the following apology: 'This book has been twelve years in the making, as my research and writing were trying to catch up with an object of study expanding faster than my work capacity' (1996: xv).

The proliferation of ICTs over the last few decades has inspired a vast amount of hyperbole about the new world we may be creating (eg: de Kare-Silver 2000; Gates 1996; Warwick 1999). Many claim that a revolution is taking place of the same magnitude, and with the same social upheaval as the industrial revolution (Sivanandan 1982; Toffler 1974; etc) and in industrialised countries, we are said to be moving towards a new social order where information is the prime commodity (Bell 1973; Castells 1996; 1997; 2000) and telecommunications are the 'true catalyst for change' (Martin 1995: 2). The new millennium then is speculatively described in terms of the technological possibilities it will herald, and the corresponding changes in the way we will all live our lives. The resulting utopian or apocalyptic visions are growing all too familiar.

Even when technology's beneficial social effects are questioned, it is frequently assumed that disabled people will inevitably reap its rewards. David Lyon for example whilst stressing that 'the easy slide from discussing the technical breakthrough to proclaiming its social benefits is simply unwarranted' (1988: 156), also singles out disabled people as having 'good reason to be grateful for the effects of the silicon chip' (vii). Likewise, Joshua Meyrowitz (1985: 118) speculates that electronic media of communication offer a new form of social access and movement to those 'whose social place was once shaped, at least in part, by physical isolation from the larger world' such as women and disabled people. Politicians make similar pronouncements. John Battle, when Minister for Science and Technology, highlighted the potential benefits of broadband interactive television for disabled older people, rather than 'conjuring up a picture of the coming miasma of home shopping channels' (Rosen and O'Neill 1997: 2), and Nicholas Scott, the former Conservative Minister for Disabled People claimed in 1990 that advances in information technology offered disabled people 'unlimited prospects for the future' (Cornes 1991: 98).

What of disabled people's stance on technology? Many disabled people seem equally enthusiastic about our future prospects, claiming for example that with the appropriate technology we can become part of the 'mainstream of life' (UPIAS 1981: 1). Others voice concerns that technology can be used in oppressive ways (Oliver 1978; Corker and French 1999; Zola 1982). It is vital then for disabled people to 'develop a critical appreciation of the limits of technological solutions' (Gleeson 1999b: 99). There is a small but growing body of work within disability studies which emphasises technology's 'double-edged nature' (Oliver 1990: 126) and stresses that it can be 'both oppressive and emancipatory, depending on the social uses to which it is put' (Gleeson 1999b: 104). This stance is not peculiar to disability theorists. Anthony Giddens (1998: 43) observes that both left and right wing thinkers now accept 'the double-edged nature of science and technology, which generate great benefits but also create new risks and uncertainties'. We cannot therefore rely on technology to liberate us.

ORGANISING FOR THE TWENTY FIRST CENTURY

Technology is not however our only hope for the future. Disabled people around the globe are more than ready to challenge their exclusion, and are forming organisations and coalitions that are ready to take on governments and corporations alike. In recognition of our collective oppression, over the last thirty years disabled people in the UK have organised together across impairment categories to demand changes to social structures (Campbell 1997). Instrumental in this new collective self-confidence, has been the 'fight to redefine disability as a form of oppression, not a biological medical condition' (Sheldon 1999: 644). In demonstrating that biology is not destiny, the resulting social model of disability offers us new ways to understand our history, account for our present, and imagine our future (see Chapter Two for a fuller discussion). Older people too are organising collectively, sometimes with dramatic results. In The United States for example, older people's organisations like the Grey Panthers and the American Association of Retired Persons (AARP) are becoming powerful lobbying groups. The AARP has successfully campaigned for changes in the law to make age discrimination in employment unlawful (Arber and Ginn 1991). Forms of globalised counter-hegemonic resistance are also emerging, often assisted by the new communication systems (Castells 1997; Starr 2000; Walch 1999). It is said that these progressive social movements will form an integral part of the twenty first century landscape (Castells 1997), and may hold the key to its transformation. Disabled people and their organisations could have an important role to play.

GENERAL OUTLINE OF THE STUDY

In the style of all such enterprises, Chapter Two will focus on the current literature. It will begin by discussing theories of disability, and the concepts of multiple oppression and ageism. It will then critically evaluate the theory that technology 'is the force which maps our future... over which we have little control' (Loader 1998:

8), along with other accounts of the relationship between the technical and the social. In so doing, it will consider which theoretical stance provides the most useful way forward for disabled people and their organisations. Claims for technology's double-edged nature will also be evaluated. Finally, the scene will be set for subsequent chapters through an interrogation of the concepts of use-value and need, and the notions of independence and dependence.

Whilst imagining the future can be a worthwhile project, there is an abundance of ill-informed speculation about the promises and perils of new communication technology for disabled people, and an absence of grounded, empirically based theorising. Hence this thesis is rooted in an empirical research project. As will be described in Chapter Three, primary data were generated through participant observation, focus groups and individual depth interviews with disabled people. Experience is a 'necessary starting point' (Kelly *et al.* 1994: 29) when studying oppression, and a proper understanding of oppressive structures and practices 'is only possible when it is informed by the personal experiences of disabled people' (Priestley 1998: 85). As the experts on their own situation, the disabled research participants were therefore given an opportunity to share their experiences of communication systems.

However, experience must not be viewed simply as 'an end in itself' (Kelly *et al.* 1994: 29) as disabling barriers have an existence outside people's experiences of them (Priestley 1998). The task of the 'sociological imagination', according to C. Wright Mills (1959: 8) is to draw links between 'personal troubles of milieu', and matters that go beyond the individual - 'public issues of social structure'. Neither individual experiences, nor the history of society in any particular epoch can be understood without understanding both. Hence Barnes *et al.* (1999: 36) stress that:

A sociological framework for studying disability must be multi-level so that it incorporates analyses of the experience of disability at the individual level, the social construction of disability and associated 'middle-range' theorizing, together with the broader analysis of societal power and social inequalities.

Likewise, I have argued (Sheldon 1999), that the disabled people's movement could usefully employ the approach advocated by bell hooks (1984: 25), an approach which examines 'both the personal that is political, the politics of society as a whole, and global revolutionary politics'. This global aspect is becoming increasingly important in a historical period where the nation state is said to be of 'decreasing relevance' (Castells 1997: 269). As Jim Walch (1999) suggests, we cannot understand the politics of information technology on less than a global basis. However, the state still exercises considerable control over the technologies available in a given society, 'by either stalling, unleashing, or leading technological innovation' (Castells 1996: 13). Despite the dismantling of the social contract, it also plays a significant role in the lives of most disabled people, and older people are more dependent on state policy than those who are younger (Estes 1991). The influence of the British government in determining the future outcomes of both communication systems, and disabled and older people's struggles for freedom, cannot therefore be overlooked. Hence I have set out to position the research participants' contributions within firstly, the national social and political environment, and secondly, within the emergent 'global corporate hegemony' (Starr 2000: ix).

There are two key themes that underpin this thesis: the first discussed in Chapters Four and Five, concerns the important issue of access to communication systems. The second, examined in the subsequent three chapters, relates to use-value and need. Disabled people have long been denied access to the technology that others take for granted, and there is little evidence that this exclusion is dissipating as we launch into the new millennium. Many writers within disability studies have been critical of the undue emphasis placed on the *potential* of technology for improving disabled people's lot (Oliver 1978; 1990; Roulstone 1993; Schworles 1983; Zola 1982). As Alan Roulstone (1993: 247) suggests, this focus on technical possibilities, 'where the latest device is heralded as the new saviour for disabled people... can serve to obscure the equally significant issue of *access* to technology'. Access to communication systems then is a crucial yet lamentably under researched area.

Of the small body of research that has addressed technological access, much has considered the problem at a global level (Jouet and Coudray 1991; Schworles 1983;

Walch 1999). A UNESCO report from the early 1990's identified various groups which are

partly debarred from markets offering the most advanced communication and information services, either on account of their age, low standard of education, or social acculturation. The new technologies could therefore be said to be creating new forms of social segmentation between the information rich and information poor. (Jouet and Coudray 1991: 51)

Both globally and nationally, this new form of social segmentation will more than likely mirror and perpetuate existing inequalities, since 'the information poverty of particular groups within society clearly reflects the distribution of power in society generally' (Cassell 1990: 166). Hence, information poverty is a problem facing many already disadvantaged groups as we move into the third millennium. The potential may exist then for increased polarisation between rich and poor, as the disadvantage that many face is further entrenched. This polarisation will inevitably take hold both between and within social groupings. Hence whilst some disabled people may prosper, others could fall yet further behind.

The disability category is socially constructed, and inherently fluid, shifting with global changes in the capitalist system. The ascendancy of information and communication technology may facilitate such a shift. Hence the boundaries of the 'disabled' category may be redrawn in the future. The primacy of written communication in Western society led to the pathologising of those with difficulties in reading and writing, and the identification of dyslexia as a significant impairment. Perhaps then an equivalent impairment might be identified to denote those who are ill equipped to manipulate the new communication systems. Impairment has both historical and geographical specificity, and as Vic Finkelstein (1997: 1) proposes, '(t)he micro-electronic revolution... appears to be revolutionising the meaning of impairment once again, as well as disabling new groups of people with abilities'.

As Chapters Four and Five will demonstrate however, there are access issues which make the current category of 'disabled people' particularly vulnerable to this new form of social exclusion. These must be addressed as a matter of urgency or the disadvantage faced by many disabled people will be compounded. If this technology

really is changing our world, then 'it is extremely important, from a democratic viewpoint, that the basic tools of this reshaping and perceiving are accessible to all' (Walch 1999: 58).

'Access', like 'disability' is a term which means many things to many people, especially with regard to new technologies. In the first instance, access to technology is all too often viewed as a technical issue with technical solutions. A piece of technology becomes accessible if it is merely useable. If it is not useable by a person with a particular 'deficit', it can be physically changed. It can be made accessible. As will be considered in Chapter Four, this approach is on the whole the one favoured by corporations that manufacture and supply ICTs. An impairment is identified, its prevalence amongst potential consumers is established, then an accessibility solution is devised (BT 1996; 1999; Microsoft 2000).

Corporations are now playing a hitherto undreamed of role in global affairs (Starr 2000). As A. Sivanandan (1982: 155) suggests, 'in as much as liberal democracy was the political expression of the old industrial revolution, the corporate state is the necessary expression of the new'. In the last two decades of the twentieth century, states all around the globe set about 'deregulating markets and privatizing public companies' (Castells 1996: 89). This was especially true of the more profitable sectors. Hence the telecommunications industry both in Britain and abroad has undergone a period of deregulation and liberalisation. Provision for disabled people in Britain is now subject to market forces, with limited regulation by a new watchdog body, the Office of Telecommunications (OFTEL). Companies are politely encouraged to recognise the potential of 'the sizeable market opportunity represented by elderly and disabled consumers' (DIEL 1998: 1), and those disabled people who can afford it are gaining rights as consumers (Albrecht 1992). Physical access to communication systems is thus in the hands of the business sector, and the regulator, and hence overall access and availability is frequently seen to be dependent solely on their efforts (DIEL 1998).

Whilst terrestrial telephone companies are to an extent overseen by OFTEL, the new mobile phone and IT companies are relatively unfettered. Any commitment to accessible design is therefore completely voluntary, and primarily motivated by a

desire to tap previously unexploited markets. Companies like Microsoft are effusive in their commitment to 'universal design' principles, and have adopted a corporate policy 'that takes responsibility for making accessible software' (Microsoft 2000: 1). Whilst it is true that certain gains have been made, it seems unlikely that the free market will ever give disabled people full inclusion and equal access in the new communications marketplace. Chapter Four will consider these issues further.

In Chapter Five, the disabled people's movement's conception of accessibility will be examined. In the UK, the movement has organised around the premise that no one aspect of the disablement of people with impairments should be treated in isolation. This was first argued over twenty-five years ago in relation to incomes (UPIAS 1976), but is equally true today when discussing technological access. As Michael Oliver (1995: 23) suggests, '(i)f we want to be included into twenty-first century society then we have to be prepared to recognise the extent and the totality of the oppression and exclusion we face'. This approach suggests that as well as considering access to technology as a purely *technological* problem, other aspects of disabled people's exclusion from communication systems must also be considered. It is impossible to evaluate issues of access to IT and communication systems in a meaningful way without also considering the larger context of access to the wider world of employment, education, housing, transport, the built environment and so on. Equal access to the beneficial use of communication systems, can only be secured along with the removal of these more traditional disabling barriers (Sheldon 1998a; Roulstone 1998a, 1998b). By assessing barriers within these two broad areas I hope to highlight ways in which both technologists and policy makers can assist disabled people's inclusion in the new millennium.

Barriers to access are only a problem if you desire to do that which you are prevented from doing. Hence whilst a consideration of access is vital, it is not sufficient. We cannot assume that all people want to use ICTs, or indeed, see any utility in doing so. Why then *do* disabled people choose to use communication systems? Why do they sometimes *reject* their use? These issues will be addressed in Chapters Six, Seven and Eight.

It has been noted that there are just two ways of creating contact between human beings and their world: 'One brings human beings to the experience and the other brings the experience to human beings' (Keller 1977: 295). Because of institutional discrimination, disabled people are often unable to go 'to the experience'. Communication systems however are capable of bringing a myriad of experiences to them without them having to leave their homes (eg: TIDE Project MART 1996). As will be discussed, it is here that their main use-value is often assumed to lie. Other much-vaunted use-values include their role in fostering 'independence', a concept which will be further discussed in Chapter Two. Many also predict that communication systems will offer disabled people the chance to present themselves as non-disabled, so they can 'interact with other users on an equal footing' (Gill 1996: 11).

Chapter Six will concern itself with the new 'community care' technologies, and the needs they are said to satisfy. These systems are hailed as a cost-efficient way for the state to enable disabled people to continue living safely and autonomously in their own homes. The use-values and potential *abuse-value* of telephones, community alarms and 'smart housing' will be discussed in this respect. The increasing primacy of mobile telephony as a means of advancing security and autonomy outside the home will also be considered.

Chapter Seven will focus on disabled people as consumers of information and other commodities. Information is hailed as an important right of citizenship and is a commodity of increasing importance in today's informational society. Disabled people however are often denied access to the information they need in order to function as autonomous agents. The potential role of information and communication technology (ICT) in overcoming information disability will be critically evaluated. Similarly, in the consumer society of the twenty first century, disabled people are kept away from the High Street by a variety of disabling barriers. Here too, ICTs are frequently assumed to enhance independence, by removing the necessity to negotiate these hurdles. The reality however bears further analysis. Chapter Seven will conclude with a short discussion of freedom of information and web-accessibility.

Finally we will turn our attention to the important realm of interpersonal communication. Language is said to be a basic human instinct (Pinker 1994) which is fundamental to all societies (Parsons 1964). What then becomes of individuals who are denied the opportunity to use their language skills to exchange information with others? Various studies have linked communication to both physical and psychological well-being (Tubbs and Moss 1994), and others suggest that without communication, we can never realise our full potential (Doyal and Gough 1991; Maslow 1954). Geoff Busby, head of the British Computer Society's Disability Group sees communication as a right. He contends that:

To deny people the opportunity to communicate through any of the senses, and to imprison latent thoughts and skills, is to withhold the kind of liberation which historically, man has fought and died for. (Busby 1997: 4)

Technology, another of Parsons' evolutionary universals, has made it possible for those with speech impairments to communicate using voice synthesis. Busby gave the above presentation in this way, and we are all familiar with Stephen Hawking's synthetic American accent. It has also provided the means for people to communicate in new ways, without an audience being present, first through the written word and print technology and now through information and communication technology. Chapter Eight will examine the implications of the new technologies for keeping in touch with friends and family, meeting new people, expressing oneself through various cultural forms, and finally for networking and political involvement.

The final chapter will assess how disabled people's unmet needs might best be served in the twenty first century. This chapter will include appropriate insights into if and how communication systems can be made more accessible, and more relevant to disabled people. It will suggest recommendations for corporations, policy makers and disabled people's organisations. It will also consider the important fact that the implementation of such reforms, whilst improving some disabled people's situation, will not necessarily remove the structural source of our collective disadvantage.

A NOTE ON TERMINOLOGY

A brief note on terminology seems appropriate. Throughout, I will use 'a relative rather than an absolute age vocabulary' (Bytheway 1995: 125), preferring to conceptualise people as 'older' rather than 'elderly' or 'old'; 'younger' rather than 'young'. Whilst a number of older disabled people were interviewed, I have no desire to divide them conceptually from their younger counterparts. Unless I see a reason to do otherwise, I will therefore simply refer to 'disabled people', rather than the clumsier, and more divisive, 'disabled and disabled older people'. I do not favour the terms 'people with disabilities' or the conflation of 'disability' with 'impairment'. Neither do I approve the use of the universal masculine. I have however faithfully quoted other authors and research participants who have used such language without, as some writers might, preceding each offending term with a knowing '(sic)'.

CHAPTER TWO: DISABILITY, TECHNOLOGY AND SOCIETY

In this chapter, I will discuss definitions of disability and the concepts of multiple oppression and ageism, before considering how proponents of both medical and social models of disability appear to be in agreement about the potential of technology. I will briefly consider how the sociology of science and technology can aid our understanding of the claims made about technology's promises. A historical materialist analysis of the production of the modern disability category will be discussed, as will a short and telling history of the telephone. The concepts of use-value and need will be introduced. Finally, I will consider ways in which the utilisation of technology has affected disabled people's lives in the past, and how it might affect our futures.

LOCATING 'DISABILITY' IN THE DEFINITIONAL BOG

'Disability' means different things to different people. Since the definition I will be using is only just beginning to gain widespread acceptance, it seems appropriate to trace its development. I will however keep the discussion brief, being all too aware of 'the tendency of commentators to mire themselves in a definitional bog' (Gleeson 1997: 181).

The medical model

There is substantial evidence that people with impairments have suffered discrimination for centuries in western society (Barnes 1996). Whilst the predominant view of disability was once informed by religion, since the rise of science and scientific medicine in the eighteenth century, disability in industrialised countries has

largely been seen as an individual medical problem (Barnes 1996; Finkelstein 1980; Oliver 1990). This process of medicalisation has also affected those from other disadvantaged populations, such as women (Riessman 1992) and older people (Estes and Binney 1991). Medicalisation involves two interrelated processes:

First, certain behaviours or conditions are given medical meaning - that is, defined in terms of health and illness. Second, medical practise becomes a vehicle for eliminating or controlling problematic experiences that are viewed as deviant, for the purpose of securing adherence to social norms. (Riessman 1992: 124)

Hence, medicine became an instrument of social control in the new industrial society of the eighteenth century (Zola 1972) and still exerts a powerful influence today.

According to this individual, medical, or 'personal tragedy' model of disability, people are disabled by their individual impairments, and it is the role of medicine and psychology to restore them to 'normality'. Oliver (1990) explains this predominant view of disability in terms of the Gramscian notion of hegemony (Gramsci 1971). The hegemony currently defining disability in Western countries is thus said to consist of the ideologies of individualism and medicalisation, and the 'personal tragedy theory underpinning much social policy' (Oliver 1990: 44). By focussing its attention purely on the impaired individual and neglecting the social context this model produces definitions which are 'partial and limited' (Oliver 1990: 5). Similar arguments have been made about the biomedical theories which 'individualize and medicalize old age' (Estes *et al.* 1984: 26). Disability is not a problem of individuals. Hence, disabled people and their organisations have rejected definitions based in biomedical thinking.

A socio-medical definition

Disabled people have looked to sociology to provide a more comprehensive definition of disability. Disability however has been largely ignored by sociologists (Barton 1996). Hence, 'disabled people are not only relegated to the margins of society, they are relegated to the margins of sociological theory as well' (Oliver 1996b: 19). The few sociologists who have concerned themselves with disability or

'chronic illness' as they prefer to call it, have conceded that the difficulties experienced by disabled people are not created entirely by their medical conditions, but are also in some way, socially produced. With these concerns in mind, Amelia Harris (1971) developed a three-fold model which distinguished between impairment, disability and handicap. A refined version of this model was later adopted by the World Health Organisation (WHO) as their International Classification of Impairments, Disabilities and Handicaps (ICIDH). The WHO/ICIDH defined the three concepts as follows:

Impairment

Any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability

Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap

A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex and social and cultural factors) for that individual. (Wood 1981: 27-29)

This classification system was enthusiastically adopted by medical sociologists, but rejected with equal enthusiasm by disabled people since it barely differed from the medical model and 'elevated impairment to the determining "cause" of disablement' (Barnes and Mercer 1996: 5). The critics insisted that disablement had nothing to do with the body and everything to do with society: 'it is not the inability to walk which disables someone but the steps into the building' (Morris 1991: 10). They further claimed that no causal link should be assumed between impairment and disadvantage. ICIDH-2, the revised version of the ICIDH produced to overcome some of these criticisms, still does not seem to be 'a tool that can be used by, and for the benefit of everyone' (Ustün *et al.* 1998: 831). It remains 'a classification of the consequences of health conditions' (Barnes *et al.* 1999: 27) and has thus been denounced as '*a threat to the disability community world wide*' (Pfeiffer 1998: 503). It seems then that a new approach is needed.

A disabled people's definition: The social model of disability

Because of the failings of both medical and socio-medical approaches to disability, disabled people themselves have formulated an alternative approach. The Union of Physically Impaired Against Segregation (UPIAS), a collective of disabled people, stated in their *Fundamental Principles of Disability* (1976: 3-4),

In our view, it is society which disables... impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the... impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have... impairments and thus excludes them from participation in the mainstream of social activities.

This two-fold classification of impairment and disability was subsequently adopted and refined by Disabled People's International (DPI) and the British Council of Organisations of Disabled People (BCODP - now the British Council of Disabled People), umbrella organisations controlled and run *by* and *for* disabled people. In line with these organisations of disabled people, I too will be adopting the UPIAS definitions of disability and impairment.

Here, no causal link is assumed between impairment and disadvantage. Disability is seen as 'wholly and exclusively social' (Oliver 1996c: 41). This redefinition of disability has already been vitally important for disabled people, both personally and politically. David Hevey (1992: 2) for example describes his discovery of the social model as an 'almost evangelical conversion', and Liz Crow (1996: 207) claims that the social model 'has saved lives'. Furthermore, its widespread acceptance could radically change disabled people's position in society. If disability is seen as a form of social oppression 'then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than individual victims of circumstance' (Oliver 1990: 2). Social policy will then tackle that collective oppression, rather than focusing on the individual.

Commonality or difference? Internal critiques of the social model

Not all disabled people are happy to be conceptualised as a homogeneous group. Hence the disabled people's movement, like many such movements before it, is now experiencing internal debates about issues of commonality and difference (Sheldon 1999). Recent critiques of the social model have advocated an emphasis on the individual experiences of disability and impairment, rather than on more collective concerns such as the removal of disabling barriers (Finkelstein 1996). These critiques focus on two main areas: the model's neglect of the role of impairment (Crow 1996; French 1993a; Morris 1991); and its failure to incorporate the experience of those disabled people who are multiply oppressed (Corbett 1994; Morris 1991; Vernon 1998; Stuart 1992). I will consider these criticisms in turn whilst describing if and how they have been incorporated into this thesis.

The social model has been criticised for focussing too heavily on the social nature of disability, and failing to acknowledge that impairment can be unpleasant in itself. However, the disabled people's movement has not actually denied that impairment can create difficulties at a personal level. Rather, it has made a 'pragmatic decision to identify and address issues that can be changed through collective action rather than medical or professional treatment' (Oliver 1996c: 48). *Disability oppression* is experienced collectively by people with a vast range of impairment experiences, and I have little desire to divide them one from another. It will at times be necessary however to discuss the implications of particular kinds of impairment for disabled people's communication systems access and usage.

For similar reasons, I am slightly uncomfortable that the current emphasis on multiple oppression could drive wedges between disabled people who share many collective concerns. It is not always helpful or desirable to divide experiences into 'an arbitrary set of socially constructed categories' (Oliver 1996a: 133), and as Gerry Zarb suggests:

characterising people's experiences in terms of multiple jeopardies may only serve to marginalise their experiences even further and divert attention from common concerns and issues. (Zarb 1993: 194)

Whilst it is undoubtedly a matter of concern that those from other oppressed groups are often left out of the equation, much of the work done in this area focuses not on changing oppressive structures, but on the subjective experiences of multiply oppressed individuals (Finkelstein 1996). It is suggested that a structural analysis may be a more fruitful way to theorise the interaction between different dimensions of oppression, since it 'highlights the way that disabled people and those from other oppressed groups need to fight for a new kind of society, and demonstrates that 'there is enormous scope for coalitions between the disability movement... and other oppressed groups' (Sheldon 1999: 646).

Whilst such an analysis has been offered with respect to disabled women (Fine and Asche 1988; Sheldon 1999), as yet disabled people who experience ageist oppression have been 'almost completely overlooked' (Zarb 1993: 186), despite the fact that they constitute the majority of the disabled population. It is suggested that:

the experience of ageing and the obstacles to older disabled peoples' self-determination must be located within a framework which acknowledges the existence of ageism and multiple oppression (Oliver and Zarb 1993: 131)

The existence of ageism often remains unacknowledged however and it is a matter of some concern that older disabled people are often excluded from research and theorising using such a perspective (notable exceptions include Priestley 2000; Zarb 1993; Zarb and Oliver 1993). Since disability and ageism are crucially interconnected, the concept of ageism will now be briefly considered:

Disability, ageism and multiple oppression

Ageing is often conceptualised as not simply a chronological, but also a physiological process (Ginn and Arber 1995). Impairment becomes the 'norm' in later life. Hence older age is equated with illness and decline, and is thus seen as 'pathological or abnormal' (Estes and Binney 1991: 118). Age discrimination is often related to this supposed incapacity, to notions of physiological ageing. It is suggested for example that age-based retirement was institutionalised as a simple, legal way for employers to

weed out expensive, unproductive workers in advance of this assumed decline (Minkler 1984). This conflation has significant ramifications for those who are both disabled and older. Older disabled people have always been included not with other disabled people, but with 'the elderly'. Hence 'when disability started to be defined as a civil rights issue during the 1980s, older disabled people tended to be excluded' (Morris 1993a: 9). Whilst an older wheelchair user is disabled by steps in much the same way as a younger wheelchair user, this may therefore be conceived of as a natural and inevitable part of the ageing process rather than as a social problem.

Ageism according to Bill Bytheway (1995) is about age and prejudice. Like any other form of oppression however, it is also about power:

It is the acting out of... prejudices and not... prejudice itself that matters. The acting out of prejudice is discrimination and when it becomes institutionalised in the power structure of this society, then we are dealing not with attitudes but with power. (Sivanandan 1990: 65)

As with disability and other forms of social oppression ageism has a structural source, and thus requires radical social change for its eradication (Minkler and Estes 1991; Phillipson 1982). Whilst disability theorists and feminists have successfully distinguished between their biological state (impairment, sex) and their socially prescribed state (disability, gender), and argued that their disadvantage is socially produced, this distinction is less clear for older people. There is then a need to distinguish between chronological age, and social age - the behaviours and attitudes thought appropriate for those of a particular chronological age (Ginn and Arber 1995), since age too 'should be treated as a sociological, not a biological, variable' (Arber and Ginn 1991: 3).

Older disabled people can thus be conceptualised as multiply oppressed since the two forms of structural oppression can be said to interact and create a new status (Vernon 1998). It may however be difficult to disentangle the two, and unproductive to try. Hence the concept of the 'disability/ ageing career' has also been utilised (Oliver 1996a; Zarb 1993), an approach which 'does not require the experiences of ageing and those of disability to be conceptually or experientially discrete and

separate' (Oliver 1996a: 138). So too, this thesis does not seek to highlight differences between these experiences, but to demonstrate the common influence of oppressive structures and practices in the lives of disabled people whatever their chronological age or gender. The differing experiences of fieldwork participants based on other dimensions of oppression were on the whole less significant than their commonalities. Bearing in mind the popularity of the multiple oppression approach, the particular affects of ageism and sexism will however be drawn out as and where appropriate.

Techno-enthusiasm and models of disability

Despite their differences, there seems to be one opinion which proponents of both medical and social models of disability share: 'Technology's potential for positive impact on disabled people is staggering' (Newman *et al.* 1983: 245). For advocates of the medical model, technology is a means of restoring disabled people to some kind of normality, of giving back the 'ability to perform an activity in the manner or within the range considered normal for a human being' (Wood 1981). Roulstone (1998a) refers to this as the 'deficit model' of technology's benefits. The social model meanwhile sees technology as enabling disabled people to be included in the 'mainstream of social and economic activity' (UPIAS 1976: 15) through the removal of disabling barriers. One model seeks to change the individual to better fit into society, the other to change society to better suit all its citizens. They appear to want the same thing, but for very different reasons. Thus, whilst there is a certain 'techno-enthusiasm that pervades much of the disability studies literature' (Gleeson 1999b: 112), disabled people have often spoken out against technologies developed in accordance with an oppressive medicalised way of thinking. The key according to Paulo Freire (1972: 103-4) is who is in control of technology:

The inhumanity of the oppressors and revolutionary humanism both make use of science. But science and technology at the service of the former are used to reduce men to the status of 'things'; at the service of the latter they are used to promote humanization. The oppressed must become Subjects of the latter process, however, lest they continue to be seen as mere objects of scientific interest.

These issues will be considered in more depth later in the chapter. Now however, in order to understand why these predictions about the implications of technology have gained such currency, it will be fruitful to look to the sociology of technology.

DISABLED PEOPLE AND THE SOCIOLOGY OF TECHNOLOGY

As there is such agreement about the potential benefits of technology for disabled people, we might expect to find some reference to the issue in the sociology of science and technology. It has long been argued that technology does not benefit all in society equally (eg: Illich 1973; Lyon 1988; Sivanandan 1982). Little of the vast body of work devoted to the sociology of science and technology has however concerned itself with inequality. Some black, feminist and Marxist scholars have addressed issues of racism, gender, class and power, but more recent developments such as actor-network theory (ANT) have not followed their lead (Cockburn 1994). Hence it is said that a 'great divide' exists between critical sociological concerns with distribution and new writings on science and technology, and that many writers in this area 'have had very little to say about class, race or gender' (Law 1991: 2). Unsurprisingly, we can add both disability and age to this list. Nonetheless, a brief discussion of trends in sociological thinking about technology tells us much about why technology is assumed to be beneficial for these groups.

Technological determinism

The dominant theory of the relationship between society and technology has been that of technological determinism - 'the assumption that technology is both autonomous and has determinate effects on society' (Jary and Jary 1995). It is a popular way for academics to conceptualise the social changes that may occur in the twenty-first century (see for example Daniel Bell's (1973) *Post Industrial Society*). Hence, the much vaunted 'information society' is often presented 'as a *fait accompli*' (Lyon 1988: 25).

William Ogburn (1964), the leading figure in the sociology of technology in the 1950s, believed that technological innovation is the moving force in social change, and that social institutions and mores are always lagging behind, vainly attempting to catch up. Many social problems are then regarded as being due to the 'culture lag' which arises when correlated parts of the culture fail to adjust to new technologies. Ogburn's brand of technological determinist or 'impact' analysis can be conceptualised in terms of 'a "billiard-ball" model in which a technological development rolls in from outside and "impacts" elements of society, which in turn "impact" one another' (Fischer 1992: 8). As will be revealed, much of the theorising about the way communication systems might affect disabled people follows in this tradition.

Technological determinist assumptions have been criticised for ignoring the social processes which guide the development and usage of technology, and the 'variety of possible social arrangements which can coexist with different types of technology' (Jary and Jary 1995: 678). Technology, according to the critics, is neither independent of society, nor does it have determinate effects. It is always developed with particular purposes in mind, yet very often has unforeseen side effects, or is used in alternative ways. As Lyon (1988: 156) points out in his critique of the information society idea, 'technological potential is not social destiny'. Arnold Pacey (1983: 24) claims that technological determinism is a massive oversimplification which 'encourages a false optimism among those who approve the kind of progress it portrays and a deep, despairing pessimism among others'. He further suggests that conventional beliefs about the inevitability of technological progress and its leading role in social development serve a political purpose:

When people think that the development of technology follows a smooth path of advance predetermined by the logic of science and technique, they are more willing to accept the advice of 'experts' and less likely to expect public participation in decisions about technology. (Pacey 1983: 26)

Since technological development occurs outside the democratic process, people therefore become dependent on others to make important technological decisions for

them. This may create particular problems for disabled people, already forced into positions of dependency by a vast array of professionals (Finkelstein 1980; 1983).

It seems then that such an approach has little to offer disabled people and those from other oppressed groups, who are already victims of a hegemonic *biological* determinism. Some critics then have taken issue with the very questions asked by theorists working within this tradition, asserting that social science has concentrated too much on the 'impact' of technological change on society, and has not asked what has shaped the technology that is having those effects (Mackenzie and Wajcman 1985). Hence an approach has developed which concentrates on the social shaping of technological systems.

The social shaping of technology

The social shaping approach insists that technology is always a form of *social* knowledge, practises and products. It is the result of conflicts and compromises, the outcomes of which depend primarily on the distribution of power and resources between different groups in society. (Wajcman 1991: 162)

The technology that is available for us to use is not necessarily the best technology for the job. Instead it is shaped by, and reflects the priorities of an oppressive, competitive society. It was for example a social and political decision to produce domestic technologies with a small nuclear family in mind - a decision which did little to assist women, or households not fitting this 'norm' (Arnold and Burr 1985). Take the refrigerator: although the gas version was arguably a better machine, having low running costs, no moving parts and being virtually silent, the market became dominated by the electric model because the companies involved in its development were larger, more powerful and more cut-throat (Cowan 1985). In more recent years, we have seen similar battles occurring in the world of IT (Lyon 1988). Vocational Rehabilitation agencies in the United States for example only fund IBM compatible equipment for disabled people, even though Apple Macintoshes are often more suitable (Hakken 1992, cited Hakken 1995).

Because it is those with power and resources who are in a position to determine which technologies are available to us, it is in the interests of the relatively powerless to reformulate the debate towards a social shaping approach. Hence, much feminist work has followed in this tradition. As Wendy Faulkner and Erik Arnold (1985: 1) suggest:

If modern technology is abhorrent to us, then realising that technology is socially produced allows us to understand that things need not be as they are. Within the broad limits imposed by the 'laws of nature', we can change the shape of technology through social forces.

Marxist writers have suggested that although technology is 'stamped with the desires and needs of the ruling class', at the same time, it is 'produced amidst conflicting social relations, and thus holds the possibility of being a tool for liberation as well as for social control' (Davis *et al.* 1997: 6). The recognition that technology is shaped by the same forces that shape disability, seems then to offer us a useful way forward. There are however problems with a purely 'social shaping' approach, as will now be considered:

Beyond technological determinism and social shaping?

Social determinisms, that reduce technological change to social relations are as inadequate as technological ones... Technological systems are both socially shaped and have social consequences, some of which go beyond the intentions inscribed in their shaping. (Lyon 2001: 24-25)

As Lyon (1988: 26) points out, it is 'naive not to acknowledge that, for most of us, the power and opportunity to influence technological development are tightly limited'. This is particularly true of oppressed groups in society. Hence Cynthia Cockburn suggests that the invisibility of women has increased with the shift from technological impact to social shaping studies: 'For a hard fact remains that, in matters of technological change, women are more impacted upon than impacting' (1994: 38). The same is true of disabled people and those from other oppressed groups. It seems

pragmatic then to assume a position which takes elements from both traditions. Hence, within disability studies, Brendan Gleeson (1999: 107) sees technology 'both as a reflection of social relations, and as a powerful influence upon social arrangements'. This is the position which underpins this thesis.

I am aware that not all would support such a distinction between the technological and the social, bound together as they are 'in a mutual process of construction' (Lyon 2001: 23). Castells for example suggests that 'the dilemma of technological determinism is probably a false problem, since technology *is* society, and society cannot be understood or represented without its technological tools' (1996: 5). This idea is central to ANT which proposes a 'non-dualistic account of the relation between 'society' and 'technology"' (Prout 1996: 198). As Cockburn (1994: 43) points out however, ANT is characterised 'less by liberatory politics than by an enthusiasm for the minutiae of technical decision making as intellectual puzzle and human drama'. It is also in danger of ignoring structural relations. As such, it is perhaps less easily manipulated to serve disabled people's ends, and will not therefore be considered further.

The work of Castells in his trilogy *The Information Age: Economy, Society and Culture* (1996; 1997; 2000) does merit further attention however. Whilst proposing that 'technology does not determine society' (1996: 5), he nonetheless 'insists on its importance in social change' (Stern 2000: 100). His lengthy thesis seeks to explain the structure and dynamics of the 'network society' - the new global order formed by the emergence of ICTs alongside changes within the capitalist system. The production and dissemination of knowledge are seen as replacing the production of goods and services, as 'informationalism' takes over from industrialism as the dominant mode of production. This new emergent society is 'both capitalist and informational' (1996: 13). It is also global, since new patterns or 'networks' of global relations and organisation are possible using the new technologies. Hence 'for the first time in history, the capitalist mode of production shapes social relationships over the entire planet' (1996: 471). The rise of global social movements based on collective identities is also charted (1997). Castells' work has been successfully utilised within disability

studies by writers such as Bob Sapey (2000), especially with regard to employment and welfare provision. It will also be returned to in this thesis as appropriate.

Other writers within disability studies have straddled the divide between technological determinist and social shaping approaches by utilising a historical materialist framework to explore the relationship between changes in the mode of production and changes in the social position of impaired people (Finkelstein 1980; Gleeson 1997; Oliver 1990). These analyses are invaluable in demonstrating the socially produced nature of both disability and technology, and also serve to illustrate that whilst social change is related to technological innovation, the final outcomes 'are the result not of mere technological impacts but of a subtle and complex interplay between technology and society' (Lyon 1988: 41). Hence we will now embark on a short history lesson.

A HISTORICAL MATERIALIST ANALYSIS

The industrial revolution in Britain marked a time of great technological innovation, and enormous economic and social upheaval. It is argued that disability in its present form emerged at this time (Barnes 1996; Finkelstein 1980; Gleeson 1997; Oliver 1990), with the growth of the commodity labour market a key factor in the process of disablement (Gleeson 1997). As Oliver (1996a: 127) suggests:

Whatever the fate of disabled people before the advent of capitalist society and whatever their fate will be in the brave new world of the twenty-first century, with its coming they suffered economic and social exclusion. As a consequence of this exclusion disability was produced in a particular form: as an individual problem requiring medical treatment.

Finkelstein (1980) elaborates a three phase model of historical development, with *Phase 1* referring to the feudal, pre-industrialist period, *Phase 2* to capitalist society, and *Phase 3* to the egalitarian society towards which he predicts we will eventually move. These loose historical phases are outlined below.

Impaired people and feudalism

Finkelstein's *Phase 1* was essentially a rural economy, where the economic base was predominantly agricultural. This period also saw the emergence of mercantile capitalism, where wealth was accumulated through buying and selling of goods. Hence, small cottage-based industry developed to provide goods for sale, barter and use within the family. Any income thus supplemented, or was supplemented by 'some direct access to the means of production' (Hobsbawm 1999: 63). Those with impairments lived within their communities, and contributed what they were able to the production process. They could for instance spin, weave or cobble in their homes, using technology which was easily constructed or adapted to suit their requirements (Finkelstein 1983; Gleeson 1999b), participate in agricultural tasks (Topliss 1975) or enter the 'profession' of begging (Finkelstein 1980). Whatever their chosen activities, Finkelstein asserts that impaired people were seen as being responsible for their own actions, and as having a right to live in the community. Despite the hardships they may have endured, they were autonomous 'citizens' with both rights and responsibilities, since there was 'little, if any, material basis for disability discrimination in feudal society' (Gleeson 1999b: 108).

The rise of capitalism, the rise of disability

Merchants began to want more control over the production process than was possible with home work, so they put people together in organised workshops. Hence the factory system was born - 'the hallmark of industrial capitalism' (Arnold and Faulkner 1985: 40). This period marks *Phase 2* of Finkelstein's model. By housing workers under one roof, merchants were able to enforce longer hours and a faster, standardised pace of work. With the rise of the factory it is argued, those with impairments began to be excluded from the production process. Having been used to working flexibly and at their own pace, they were often poorly equipped to deal with the 'speed of factory work, the enforced discipline, the timekeeping and production norms' (Ryan and Thomas 1980: 101). For Gleeson (1997: 194-5) however, it was not

the rise of the factory per se, but the increasing primacy of Marx's 'law of value' that created this exclusion:

Market relations, and the commodification of labour, introduced a social evaluation of work - the law of value - into peasant households which had previously been relatively autonomous production units. The increasing social authority of the law of value meant the submission of peasant households to an abstract external force (market relations) which appraised the worth of individual labour in terms of average productivity standards. From the first, this competitive, social evaluation of individual labour-power meant that 'slower', 'weaker' or more inflexible workers were devalued in terms of their potential for paid work.

The law of value is important in both capitalist production and consumption, and will be returned to again in the discussion of 'use-values'.

Back in the factory, owners were able to further increase efficiency through imposing a new division of labour. The various operations were separated, and the workers 'divided, classified and grouped according to their particular qualities' (Marx 1976: 469). The workforce was thus divided into a hierarchy with a corresponding scale of wages, and natural endowments were the foundations on which this division of labour was built. Disabled and older people whose speed of work may have been below average would have been at the bottom of the hierarchy had they been included at all. Women were also excluded through this new division of labour, and consigned to the private space of the home (Sheldon 1999).

Whilst the machinery in the early factories was very simple and mainly made of wood (Pacey 1983), there was quickly a demand for more efficient machinery to increase the surplus value accruing to the factory owners, and to maintain their share of the market by keeping prices at a competitive level. Hence changes in the organisation (relations) of production were accompanied by changes in the technology (means) of production. This mechanisation of production initially led to an extension of the working day in order to make the fullest use of the expensive equipment. Parliamentary legislation however enforced a shorter working day, giving an increased urgency to the drive towards automation:

from the moment that it was made impossible once and for all to increase the working day, capital threw itself with all its might, and in full awareness of the situation, into the production of relative surplus value by speeding up the development of the machine system. (Marx 1976: 534)

The new machinery would have been designed and produced for use by the 'standard' worker, and would have been inaccessible to many with impairments. Furthermore, employers could justify the high capital costs of this machinery only if it were 'operated at speeds that led inevitably to the obsolescence of workers too old to maintain required levels of productivity' (Graebner 1984: 177-8). Hence both disabled and older people were progressively excluded from the production process, in part at least because of the changing nature of technology.

Alongside these changes in the mode of production came equally profound changes in society which had influence on the experience of disability. As Finkelstein (1980: 10) suggests, *Phase 2* was 'generated by the creation of a new productive technology - large scale production lines geared to able bodied norms', and 'inaugurated with the growth of hospital based medicine and the creation of large asylums'. Hence, the new mode of production and the drift towards urban centres precipitated the growth of a large class of 'industrial rejects' for whom special provision had to be made (Jones and Tillotson 1965, cited Oliver 1990)

The transition from feudalism to capitalism incorporated changes in both the system of production, and the rules of distribution. Labour became the new distributive mechanism, with people receiving wages 'determined by the value and amount of work they performed' (Stone 1984: 34). For those unable or unwilling to work in the new factories, the solution was increasingly the institution - the new means of enforced segregation from the rest of society. Although poor relief was already in existence, the 1834 Poor Law Amendment Act introduced new principles such as the prohibition against 'outdoor relief' - the giving of assistance outside the workhouse - for all but children, the sick, the insane, 'defectives', and the aged and infirm. Hence the 'workhouse test' was introduced to distinguish between the deserving poor and the merely indolent - the forerunner of today's oppressive assessment procedures for would-be disability benefit claimants.

Oliver (1990: 32) whilst acknowledging the role played by the mode of production in producing the modern disability category, asserts that the 'mode of thought' also plays a role. Hence it is not technology alone which 'impacted' on society and created these social changes, but a complex interrelationship between the economy, beliefs such as the Protestant work ethic (Weber 1930) and the rise of scientific medicine and liberal utilitarianism.

A brave new world? Finkelstein's 'Phase 3'

As we have seen, there has been a proliferation of forecasts about the pleasures and/or perils that the future will hold. Much of this futurology hinges on the proposed 'impact' of new technology. Following in this tradition, Finkelstein's *Phase 3* is described as a utopian world where disability, as created in *Phase 2*, is eliminated through the development and utilisation of technology. He claims that disabled people whilst already more able to live autonomously because of technological innovation, are still prevented from further social participation:

What stands in the way, (at a time when the material and technological basis for solving the human and material needs of disabled people have mostly been solved) is the prevalence of phase two attitudes and relationships. (Finkelstein 1980: 39)

Here, Finkelstein seems to be proposing a 'cultural lag' akin to that described by Ogburn (1964) - although technology has changed to such an extent that impaired people no longer need be at a disadvantage, attitude changes are lagging behind and preventing their full participation in society. The assumption seems to be that these negative attitudes will erode over time, and that technology will eventually deliver its benefits to disabled people unhindered. This is of course classic technological determinism.

Gleeson (1997: 191) comments on 'the rather enigmatic character of Finkelstein's... historiography'. It is indeed easy to criticise Finkelstein's model for its simplicity, its historical inaccuracy, and its unquestioning belief that 'technological developments will liberate disabled people and integrate them back into society'

(Oliver 1990: 29). He is also very unclear about the exact nature of *Phase 3* society. Does it refer to the much-vaunted post-industrial or information society, or does it perhaps mark the beginning of the transition to socialism? It has been suggested that Finkelstein's model should simply be regarded as an 'aid to understanding rather than an accurate historical statement' (Barnes 1996: 47). It very effectively demonstrates the social nature of disability, and how attitudes are shaped by economic and political factors (Barnes 1990). It also raises important questions about the emancipatory potential of technology in disabled people's lives, and the possibility that technology can redefine the notion of disability. Despite flaws then, such an approach may well be a productive way to conceive of current changes, since they too are said to follow the model of historical materialism. (Davis *et al.* 1997)

Before we end our history lesson, a short consideration of the emergence of telephony seems appropriate, since it illuminates much about disabled people's current exclusion from communication systems:

THE TELEPHONE: A HISTORICAL PERSPECTIVE ON ACCESS

Alexander Graham Bell, credited with the invention of the telephone was trained as a teacher of deaf pupils - and, in some accounts, was also married to a deaf woman. He set out to develop a sound amplifier which could be used as a hearing aid. The device was not a success as intended, but it was capable of transmitting sound over large distances via electric wires. Hence the telephone was born, and received its patent in 1876. Somewhat ironically for deaf people, the telephone was totally inaccessible to them for almost a century. Although text messaging has now become ubiquitous amongst younger mobile phone users, it was not until the 1960s that text telephony was first tried out. It is claimed that this was 'an example of society's priorities: the technology was there for a very long time before it was made available to those who perhaps needed it most: the disabled part of the population' (Lindstrom and McEwan 1991: 449). Likewise, the forerunner of today's videophone was first demonstrated as

early as 1927, but these systems have only recently become commercially available (Short *et al.* 1976).

Bell was not only a great inventor, he was also a eugenicist and a crusader against the use of sign language by deaf people:

Fearing the emergence of a 'deaf variety' of humans and therefore seeking to discourage intermarriage among deaf people, Bell proposed that residential schools should be abolished, education through the medium of sign language should be forbidden, and the Deaf should be prohibited from teaching the deaf. (Davis 1995: 18)

With this eugenic commitment to keeping disabled people isolated from each other, it seems likely that Bell would have opposed the introduction of any device which allowed deaf people to communicate with each other via the telephone lines - especially using non-oral language. Such disablist concerns probably explain the long delay between the invention of the standard telephone, and the emergence of text-telephony and other systems accessible to disabled people. Alternatively, it is suggested that this exclusion was inadvertent: 'as hearing people realised what a marvellous facility had been offered to them, and forgot about those who were deaf' (Shipley and Gill 2000: 12).

Gleeson (1999b) is rightly critical of this 'thoughtless design' approach which is very evident in the disability studies literature (eg: Topliss 1982). In viewing inaccessibility as a 'mishap' perpetrated by individual designers it effectively denies that inaccessibility has a structural origin. Discriminatory design is thus seen as an 'accident' to be corrected through legislation, 'rather than the observable form of deeper material and ideological structures of discrimination' (Gleeson 1999b: 105). Whatever the initial reasons for disabled people's exclusion from telecommunications, it is clearly inexcusable to allow this exclusion to continue into the twenty first century. It would be misleading however to suggest that technology necessarily 'represents the march of progress and that the only downside is the absence of a ticket for the journey' (Loader 1998: 6). Accessibility is only one of our problems. The uses to which technology is put can also be oppressive. The concept of usefulness or 'use-value' will now be considered.

USE-VALUE OR USELESS-VALUE, TRUE NEEDS OR FALSE NEEDS

As discussed above Gleeson (1997) usefully invokes Marx's concept of value to illuminate the material basis for disabled peoples' exclusion from capitalist production. It is also a concept with great centrality in relation to consumption - the 'conceptual coin's flipside to production' (Edwards 2000: 14), and something which disabled people, along with the rest of society are increasingly forced into. It is in this context that I will now consider the concept, in relation to the utility of communication systems for disabled people.

Telephones, computers and now even 'care' packages are all commodities, produced by wage labour for exchange in the marketplace. As such, according to Marx, they have two powers. First, they can be exchanged for other commodities (most notably the 'money' commodity) - they have an exchange value (or 'value') (Bottomore 1991). Second, they have properties which satisfy 'human wants of some sort or another' (Marx 1976: 35) - they have use-value. Use value is most commonly defined in terms of needs (Heller 1976). As Marx (1962: 42) suggests: 'The use-value of particular commodities depends on the particular need which each satisfies'. Whilst Marx's formulation implies that without use value, there can be no exchange value, the 'magnitude of the latter is not determined by use value' (Jary and Jary 1995: 713). The labour power that goes to make any commodity also has an exchange value, although it does not correspond to the exchange value of the products it creates. Profit, or 'surplus value' is created through this process, as the overheads in terms of wages and other fixed costs, are always less than the exchange value of the finished commodity - hence Marx's theory of exploitation (Bottomore 1991).

Use-value is not the sole property of commodities however. I can equally fashion a walking stick from a tree branch as purchase one in a shop; if I am hungry, I can eat wild nuts and berries or order a take-away. However, according to Ivan Illich (1978: 33), needs have now 'become almost codeterminous with commodities', thus creating a 'rigid interdependence of needs and market'. Illich uses the term radical monopoly to describe this interdependence. A radical monopoly is the dominance of one type of *product* not one type of brand. It occurs when one industrial production process

'exercises an exclusive control over the satisfaction of a pressing need, and excludes nonindustrial activities from competition' (Illich, 1973: 52). Radical monopoly, thus

imposes compulsory consumption and thereby restricts personal autonomy. It constitutes a special kind of social control because it is enforced by means of the imposed consumption of a standard product that only large institutions can provide. (Illich 1973: 52-3)

Since commodities are turned into basic necessities, with a unit cost beyond what many can afford, radical monopoly creates 'new classes of scarcity and a new device to classify people according to the level of their consumption' (p. 54). Inevitably then, it exacerbates poverty levels, and increases polarisation between rich and poor. As will be considered presently, society's increasing dependence on industrial products such as mobile phones and computers, may precipitate the emergence of another radical monopoly. This will have terrible implications for those who are poor and oppressed, and, as Illich (1973) notes, will probably be discovered only when it is too late.

To say then that a commodity has use-value does *not* therefore imply that the needs it satisfies could not be satisfied in other ways without recourse to consumption. These may often be more appropriate ways, since the design of commodities does not always follow from an identified human need. This is especially true of modern technology, which ideally,

should be developed to meet needs and solve problems. This means that the needs and problems should first be identified and then the search for appropriate technology can begin. (Shalinsky 1989: 65)

Instead however, technologists rarely work in this way (Pacey 1983), and new technology is frequently hailed as an answer, whilst the question remains a mystery.

Likewise, not all commodities are particularly useful. This does not however stop them from being purchased. Frankfurt School theorists like Herbert Marcuse (1964: 19) explain the consumption of such commodities in terms of 'false needs' - needs which 'have a societal content and function which are determined by external powers

over which the individual has no control'. Goods may then be purchased for social reasons, even though they effectively have *useless* value. This distinction between true and false needs, is equivalent to that more commonly made between 'needs' and 'wants'. Needs, which tend to be defined as objective, are distinguished from 'wants' which are 'not universal but regarded as relative, contingent, pluralistic' (Slater 1998: 317). Need satisfaction then is 'essential to the continued existence or identity of a body, person or social order' (Slater 1998: 315). Hence Marx distinguishes between natural or necessary needs and socially produced needs. These natural or necessary needs 'refer to the simple maintenance of human life (self-preservation)' (Heller 1976: 31). The mode of need satisfaction however, gives even natural needs a socially produced character. Hence the hunger which is satisfied with raw meat is contrasted with that which is satisfied with a knife and fork (Marx 1973). Likewise, as will be discussed below, in today's society, we could perhaps distinguish between the need for human security which is satisfied through close family or kinship networks, and that which is satisfied using a community alarm system.

'Need' is a highly contested concept (Langan 1998). As Len Doyal and Ian Gough (1991: 1) suggest:

Sometimes it is employed in attempts to justify social policies (e.g. 'The frail elderly need more sheltered housing') and to criticise them (e.g. 'British schooling does not meet the needs of its children')... Yet the idea of need has also been widely abused. On the grounds of their expertise about the satisfaction of human need, planners have justified and implemented disastrous social policies.

Disabled people and others from oppressed groups are particularly affected by this abuse of the concept. All humans share the same basic needs (Barnes 2000; Marks 1999; Shakespeare 2000). A distinction can be made however between people whose needs are automatically met, 'and are therefore seen as having no needs'; and people whose needs are not met and must therefore 'make a *special* plea for assistance and support' (Marks 1999: 97). Disabled people fall into the latter category. Subject to numerous professional 'need' assessments which use a 'narrow medical frame of reference' (Sim *et al.* 1998: 58), they are seldom in a position to define and satisfy their own unmet needs. The Derbyshire Coalition of Disabled People (DCODP)

attempted to challenge this 'professional obsession with assessment of needs' (Finkelstein 1998: 41) by drawing up their own list of the seven needs of disabled people: information, access, housing, technical aids, personal assistance, counselling and transport (Davis and Mullender 1993). Arguably though,

Until the social model of disability is more widely accepted, disabled people will continue to find difficulty in gaining a successful response to needs which they have defined; while the medical model of disability holds sway it will continue to categorise the needs of disabled people and in doing so disempower them. (Sim *et al.* 1998: 53-54)

Many western societies now boast complex welfare systems to distribute goods to those excluded from the labour market. John McKnight (1977) argues that the resulting professionalised assumptions about need often have disabling effects, since need is defined as a personal deficiency. Hence it is suggested that the failure of the welfare state to adequately serve disabled people is due in large part to the central role given to the concept of need. Disabled people have called instead for the *rights* 'to appropriate welfare services to meet their own self-defined needs' (Oliver 1996a: 74), since historically, their rights have been 'translated by the welfare state into needs' (Sapey 2000: 630). This 'rights-based language' may however prove equally problematic, since it: 'represents an individualised, ultimately depoliticised, discourse on human need, for it acknowledges only persons who make a claim against the collectivity' (Robertson 1997: 431).

Questions about the primacy of need as a distributive system will doubtless continue to inform debates about the future of the welfare state into the twenty first century. They will not however be pursued further here. Nonetheless, a discussion of use-value necessitates the invoking of the concept of need. If a commodity such as a telephone or a computer has use-value, it must be a satisfier of some human need. The concept must be politicised if it is to truly reflect disabled people's priorities, a process which involves curbing 'the power of the "experts" and the growth of the "therapeutic state"' (Robertson 1997: 441). Hence disabled people and their organisations must be enabled to determine their own needs, and decide how these unmet needs would be best satisfied. The disabled people involved in the fieldwork

were free to express if and how they saw communication systems as satisfying their self-defined needs. The use-values they described were in keeping with those basic human needs elaborated by Doyal and Gough whose *Theory of Human Need* (1991: 54) suggests that:

since physical survival and personal autonomy are the preconditions for any individual action in any culture, they constitute the most basic human needs - those which must be satisfied to some degree before actors can effectively participate in their form of life to achieve any other valued goals.

To be autonomous in its most 'minimal' sense, means 'to have the ability to make informed choices about what should be done and how to go about doing it' (Doyal and Gough 1991: 53). However, Doyal and Gough shy away from an atomistic focus on mere 'freedom of agency', by emphasising 'the interdependence between individual need-satisfaction and societal preconditions' (1991: 89). All in society have a duty to help all others to optimise their levels of need satisfaction, with as the end goal, human liberation: 'the satisfaction of the health and autonomy needs of as many humans as possible to the highest sustainable levels' (Doyal and Gough 1991: 111). Note that the originally cited need for 'physical survival' has now been replaced with 'health' needs. As has been noted elsewhere (Abberley 1996), *A Theory of Human Need* adopts a medical model perspective on disability, and explicitly rejects social model thinking. The debate it raises is however, according to Abberley (1996: 76), 'one from which disability theory can benefit and... develop in its own character'. This thesis will perhaps make a small contribution to this task.

How then has technology contributed to disabled people's need satisfaction? Like other oppressed groups, disabled people have long been excluded from technology that the rest of society takes for granted. At the same time however, they have become the recipients of a huge and growing 'disability business' involved in developing and marketing technologies specifically for their ascribed needs (Albrecht 1992). Many disabled people have become impaired as a direct consequence of modern technology - either as an intended consequence of military technology (Davis 1986, in Oliver 1990), or as an unintended side effect of modern transport, medical or

industrial technology (La Rocca and Turem 1978). Nevertheless, it is claimed that technology 'can be used in many ways to reduce or eliminate the effects of an impairment' (La Rocca and Turem 1978: 1), and many disabled people would not be alive today without it. As discussed previously, many in the disabled people's movement have enormous faith in the potential of technology to improve the situation of disabled people. According to the UPIAS *Policy Statement* (1981: 1): 'Britain today has the necessary knowledge and advanced technology to bring physically impaired people into the main-stream of life and enable us to contribute fully in society'. Unfortunately however, it seems that the 'necessary knowledge and advanced technology' may not be enough. It is now over twenty years since the drafting of this historic manifesto, and disabled people are still not able to 'contribute fully in society'. Undeniably disabled people's lives have improved in some respects. How much this has been due to the utilisation of technology, and how much to other factors is debatable however.

There are obvious parallels to be made between the women's movement of the 1970s and the disabled people's movement of today (Sheldon 1999). Since there is little in the disability studies literature which engages with technology, we can usefully look to feminist writings to inform such debates. In *Feminism Confronts Technology* for example, Judy Wajcman (1991: 78) considers the effects of the pill on women's societal position:

If the gains for women outweigh their losses it is because of the achievements of the women's movement and not the technology *per se*. The pill has not bought about women's liberation: women have gained control over their lives through social and political mobilization.

It may be that disabled people, like women before them, will only gain control over their lives through 'social and political mobilization', not through technology alone. We will briefly consider then whether previous technological innovations can be said to have assisted the self-emancipation of disabled people in any way.

DISABLED PEOPLE AND TECHNOLOGY: LIBERATION OR OPPRESSION?

A historical analysis of technological change suggests that it is often accompanied by increased inequality in society. Even in ancient horticultural societies, rank was associated with control of technology (Persell 1990). More recently, in areas such as Asia and Latin America, we have seen mechanised agricultural technology being introduced 'in unequal ways that have increased inequality and poverty' (Harrison 1993: 101). Since technological change helped create the disadvantage experienced by disabled people today, can we rely on technology to remedy their situation?

As described earlier, there has been some interest by women in the complex relationship between gender and technology. Much of this work has suggested that supposedly liberating medical and domestic technologies have done little or nothing to benefit women, and may even have compounded their oppression (Arnold and Burr 1985; Wajcman 1991). An examination of black people's relationship with technology reveals similar problems. The first victims of computerised labour-saving technologies are said to have been unskilled and semi-skilled workers, and for 'historic as well as racist reasons, the black workers were concentrated among these groups' (Peery 1997: 298). Hence it is suggested that:

The goals of black liberation and the high-technology revolution are in conflict, since the latter aims at maximizing efficiency - which usually takes the form of labour displacement - while the former aims at expansion of employment opportunities for the discriminated group. (Leiman 1993: 187)

A similar analysis of disabled people's relationship with technology should be of value in 'ensuring that technology is used to liberate rather than further oppress' them, and to give a clearer understanding of technology's 'double-edged nature' (Oliver 1990: 126).

The development of technologies for disabled people is seldom carried out *by* disabled people. Its development is most often underpinned by both medical and technological determinism, with their associated goals of cure and adjustment to normality. New technology for disabled people then is most widespread and securely

funded at the level of impairment, that is when applied to diagnosis, treatment and prevention. There is also massive growth in 'rehabilitation' technologies which seek to restore function. Progress is slowest however in technologies which aim to remove disabling barriers (Cornes 1991). It is worth examining each of these areas in turn, to assess whether recent innovations *for* disabled people have empowered them as intended. Medical technologies will be discussed before moving on to an assessment of rehabilitation technology and its implications for disabled people's increased independence. Finally, evidence for technology's potential to eliminate disability will be assessed.

Medical technology

Few would argue that medical technology has done nothing positive for disabled people. Many disabled people alive today would not have survived without it. Paul Abberley notes that he would have died had he been born a few years earlier, before the development of respiratory support systems (Abberley 1987). However, disabled people are generally not consulted about the development of treatment programmes. As a consequence, some treatments have arisen which disabled people do not need or want, because of medical assumptions about the value of 'normality'. Hence disabled children are subjected to painful and unnecessary surgical interventions such as limb-lengthening and cochlea ear implants in an attempt to make them more like their non-disabled peers.

Medicine also has a role to play in the prevention of impairment. Interventions such as the mass inoculation programs to eradicate diseases like polio would seem to have been extremely effective, although the development of such techniques often has the paradoxical effect of disadvantaging those who have already been impaired by a disease (Abberley 1987). Medical science is not necessarily the only factor at play in reducing the incidence of certain diseases however. Factors such as improved nutrition, and other public health measures may be equally significant (Illich 1975). Impairment is socially produced (Abberley 1987), and medical attempts to remove it

from this context mean that such economic and social factors go largely unrecognised (Crow 1996).

More recently, science has developed yet more sophisticated ways of eradicating impairment, by preventing the birth of affected fetuses. Advances in genetics coupled with a particular societal attitude towards disability, have made possible the diagnosis of particular conditions which medical science is not able to treat. Hence screening programmes have been implemented to test fetuses for conditions such as Down's Syndrome, Spina Bifida and Muscular Dystrophy. Since treatment is not an option, an abortion is often chosen if such conditions are detected. These selective abortions are legal to term if a foetus is deemed to be severely impaired, in contrast to the twenty-four week ceiling for non-impaired fetuses (Bailey 1996). Whilst the Human Genome Project was set up with the aim of identifying the functional position of each gene, the choice of which condition to try and link with which gene is a social and economic decision (Bailey 1996). Whilst there has been much debate within the disabled people's movement about the negative implications of such developments, science is not a democratic process and the scientific establishment has not considered these viewpoints (Shakespeare 1995).

It seems then that whilst medical technologies have saved countless lives, they can also be used in ways which further oppress disabled people. The story is similar for rehabilitation technologies - the solutions offered to those whose impairments cannot be treated or eradicated through medical technology. This area will now be considered:

Rehabilitation technology: Science-fact or science-fiction?

Rehabilitation technology developed as early as 500-600 BC, when early men and women made wooden prostheses from tree limbs (La Rocca and Turem 1978). There have been massive developments since, with recent innovations in robotics and ICTs making even more devices possible. There is much hyperbole surrounding these innovations. According to one commentator:

It sometimes seems as if the microprocessor was developed just to help the paralyzed, the paraplegic, and the bedridden. The impact is likely to be so revolutionary that science fiction will overlap with fact. Among the wonders that will come to pass: the blind will be able to see (albeit dimly), the physically disabled to walk (albeit slowly and with difficulty), and the paralyzed to communicate with the world. (Rosenberg 1992: 115)

The newspapers are replete with such gee-whiz pronouncements. We are for example enthusiastically told that 'Star Trek style "smart spectacles" could provide kaleidoscopic vision for the partially sighted in the next 10 years' in the form of a lightweight virtual reality headset like that worn by Geordi la Forge, a character from *Star Trek: The Next Generation* (Nelson 1997: 5). Popular science-fiction is full of images of cyborgs: beings part-human, part-machine. In the seventies television series *The Six-Billion Dollar Man* for example, the hero became super-human after being severely impaired in an accident, then rebuilt with modern technology. A similar scenario is the subject of the film *Robocop*. The William Gibson novel *Neuromancer* (1993) sees a future where non-disabled people deliberately injure themselves so they can wear more efficient, prosthetic limbs. Back in the academy, ANT has embraced the cyborg. Donna Haraway (1991: 178) calls for a 'reinvention of nature', asking: 'Why should our bodies end at our skin?' and John Law (1991) contends that since none of us found our way through last week without using machinery, we are all part machine.

According to Marshall McLuhan and Quentin Fiore (1967: 124), the science-fiction writing of today 'presents situations that enable us to perceive the potential of new technologies... Big Business has learned to tap the s-f writer'. Hence what was once merely fiction 'is now being materialised and is turning into everyday life' (Moser 2000: 215). It seems that disabled people are the test-bed for many of these innovations, turned into cyborgs by technologies such as cochlea implants and pacemakers. Do disabled people want science fiction and science fact to merge? Irving Zola (1982: 396) is cautious:

There is little understanding of what happens when bodily parts and functions are replaced by equipment. It is not an unmixed blessing. It has been found in regard

to transplants and skin grafts that the physiologic body rejects parts that it feels are alien. So, too, the psychosocial person rejects parts that it feels are alien.

He suggests that alienation can be reduced if devices can be customised by their users. By altering his leg brace, he claims 'I have made the brace more a part of me because I have altered it uniquely'. In so doing, he effectively created his own use-value.

The oft-stated aim of much rehabilitation technology is to decrease dependency and thus increase user independence. Independence, like 'disability' is however a highly contested concept, being 'at best, ambiguous, and at worst, misleading' (Corbett 1997: 90). Hence it demands further explanation.

Independence, dependence or interdependence?

In Western industrial societies, the term 'independence' has become associated with 'the ability to do things for oneself, to be self-supporting, self-reliant' (Morris 1993a: 22). Hence, those with impairments who need assistance with daily living tasks are assumed to be 'dependent'. To be dependent is 'to be subordinate, to be under the control of others' (Morris 1993a: 23). Hence those who cannot do everything for themselves 'are assumed to be unable to control their lives' (Morris 1993a: 23). This interpretation has ramifications for the way that technology is developed and deployed, since it is assumed that 'independence' can be enhanced if personal assistance is provided by a machine rather than another person (Cavalier 1987). As Sally French (1993b: 46) suggests, this can restrict rather than enrich the lives of disabled people

technological aids are a mixed blessing. I am writing this article on a word-processor which enlarges the print on the screen. It is a marvellous machine and I would not want to be without it. Yet aids can become a burden too, because other people have such faith in technology that they believe a disabled person is managing perfectly well and requires no assistance.

Unsurprisingly then many disabled people have taken issue with this oppressive interpretation, and have sought to redefine the meaning of the term 'independent'.

Rather than conflating 'independent' and 'self-sufficient', the disabled people's movement uses the term to 'indicate someone who has taken control of their life and is choosing how that life is led' (Brisenden 1998: 27). This meaning is of course very close to currently fashionable notions of personal autonomy, as described by Doyal and Gough (1991). Thus independence can be seen as a basic human need.

Since independence for everyone in today's society can only be achieved through further dependence on other people, Finkelstein (1980: 38) questions disabled peoples' assumed dependency, asking: 'how does this differ from the requirements of disabled people? The answer of course, is that it doesn't. We are *all* dependent on others. Hence various theorists discuss 'interdependence', a concept which highlights this mutual dependency. Illich (1973: 11) for example considers the 'individual freedom realized in personal interdependence'; Ann Robertson (1997: 436) claims that because we live in communities, 'we are *ipso facto* interdependent'; and Barnes (2000: 452) proposes that 'human beings are, if only by necessity, interdependent'. Interdependence is also a feature of New Labour's communitarianism. As Tony Blair (1995: 12) proposes, 'only by recognising their interdependence will individuals flourish, because the good of each does depend on the good of all'. However, such thinking has not yet trickled through to those designing rehabilitation technology: human interdependence is downplayed, and atomistic, technologically-assisted 'self-sufficiency' is still the order of the day.

Devices such as the *handy 1* rehabilitation robot now exist to take over tasks such as feeding and applying make-up. The motivation behind designing and building such devices is the belief that such technology has the potential to 'enhance the quality of life of some disabled people leading to greater personal fulfilment and enrichment of self-esteem' whilst reducing both 'the burden of care borne by carers' and the cost of 'care' (Hagan *et al.* 1997: 1). Disabled people do not seem to share this excitement (Scherer 1993; Zola 1982). It seems that the users of the equipment have been largely forgotten by the technologists. Zola (1982: 396) for example suggests that: 'To be handled by a machine or animal, where once I was handled by a person, can only be invalidating of me as a person'. Similarly, Brian tells Marcia Scherer (1993: 90),

to have your needs met by a robotic device is like saying you're subhuman. But to have someone assist you, to have that conversation, to get to know and live with someone, it's affirming your value as a human being.

Like rehabilitation robots, the new ICTs have the capacity to substantially reduce the cost of community 'care' (see Chapter Six). Community alarms, 'smart housing', and online services could mean that disabled people are less reliant on assistance from others. The financial benefits for the welfare state seem clear. It is less clear how disabled people will respond to this kind of technology. Will it facilitate 'independence' in its other sense, or restrict their choices yet more? These questions will be examined in Chapters Six, Seven and Eight. It seems likely that technological solutions to disabled people's problems may not always be appropriate. The dangers of such 'technical fixes' will be briefly considered below:

Fix this! Disability and the 'technical fix'

(I)t is obvious that there exists within certain key institutional settings, such as the design and building professions and the medical establishment, a rather uncritical faith in the power of such technologies to overcome the 'limitations of disabilities'. This faith in technology is often reflected in laws, policies, institutional arrangements and social attitudes which privilege technological solutions to the problems faced by disabled people. (Gleeson 1999b: 99)

Complex social problems are all too often presented as if they have simple, single causes, and the temptation is to look for simple solutions in the form of a 'technical fix' (Pacey 1983). Proponents of the technical fix hold that technological solutions to non-technical problems are often easier to affect than political or economic solutions. Although treating at best, only a symptom of the problem, and not the actual cause, it is argued that this kind of fix can alleviate symptoms, and buy time for an attack on the cause of the problem. Critics however point out that technical fixes or shortcuts merely serve to distract attention away from social issues which might affect genuine social change (Bereano 1976).

In recent months, certain technological advances targeted at people with impairments have been highly publicised in the media, perhaps because of celebrity

support from the likes of Christopher Reeve and Stevie Wonder. Whilst some are excited by such applications of technology, others are more cautious. Joe Korner of the RNIB for example is highly critical of the hype surrounding research into retinal implants, and stresses that 'we are not at the stage where medical solutions are solutions. We are really looking for social change' (Brown 2000: 10). Likewise, Zola (1982: 394) maintains that one of the factors preventing disabled people's full participation in the mainstream of American life is the 'overreliance on technologic solutions to personal and social problems', and others propose that technological solutions to disability can be '*a significant factor in our oppression*' (Corker and French 1999: 5). David Hakken (1995: 518), whilst recognising that technology can have great benefits for disabled people, is also very aware of the way that technical fixes can distract attention away from more pertinent issues:

There is the ... danger that the dazzle of new technology will blind society to the other, equally important needs of people with disabilities: indeed that technologies of access will come to be treated as substitutes for rather than supplements to equally important needs in the areas of rights and opportunities. Supplying people with machines can come to be a way to avoid supplying them with access and an excuse for not making public places accessible.

He claims that this is possible because of a political culture which substitutes technology for more meaningful solutions to social problems, and advocates the construction of a new technology paradigm for addressing disability.

How then to construct such a paradigm? The medical model, according to Oliver (1978: 136), 'takes an overoptimistic view of the improvements that the progress of science and technology will bring to the disabled'. As already discussed, the same could be said of many who subscribe to the social model. Oliver (1990: 126) implies however that a more critical analysis of technology's implications for disabled people would come from the disabled people's movement, which may be 'central to ensuring that technology is used to liberate rather than further oppress disabled people'. The British disabled people's movement has been at the forefront of debates around the new genetic technologies, but has as yet done little to challenge the increased emphasis on ICTs as the route to our liberation. Elsewhere however, disabled people

have begun to take action against such technical fixes. At a protest in Melbourne Australia for example, wheelchair users ran over and destroyed computers to challenge new public policies that 'emphasised the provision of technological aids - especially computers - as the answer to disabled people's social needs'. A spokesperson is said to have argued that 'the neo-liberal State Government's cuts to basic support services had created a social crisis for many disabled people that technological aids could not solve' (Gleeson 1999a: 141).

Technology then can be used in ways which both liberate and oppress, and it seems that disabled people's movements around the world are more than ready to engage with such debates. We need to step up our efforts to develop such a critical understanding. As Wiebe Bijker and John Law (1992: 306) point out:

Our technologies surround us as they have done for millennia, but never before have they been so powerful. Never before have they brought so many benefits. Never before have they had so much potential for destruction ... And never has the task of understanding those technologies - how they are shaped, how they shape us - been so urgent.

Hopefully this thesis will make a small contribution.

SUMMARY

This chapter has described the move from a medical to a social model of disability, and highlighted the technological optimism shared by both models. Trends in sociological thinking about technology have been briefly considered in the light of these optimistic forecasts. It was suggested that historically, technological change has been accompanied by changes in the status of disabled people and those from other oppressed groups. Reasons for the historical exclusion of disabled people from communication systems were also considered. The concepts of use-value and need were introduced as a means of assessing the utility of technological innovation for disabled people. Disabled people's complicated relationship with technology has been further considered, as has the need for their involvement in technological decision

making if technology is to contribute to their self-emancipation. Finally, the potential danger of attempting to solve social problems with technological solutions has been highlighted, as has the urgency for a clear understanding to be formed of the relationship between disabled people and technological systems.

As yet, the discussion has been rooted in the writings of other academics and activists. The subsequent analysis will be based not only on a literature review, but also on primary data generated through participant observation, focus groups and individual interviews. Having laid the theoretical foundations, the next step then is to justify my chosen methodology and my data generation strategies.

CHAPTER THREE: RESEARCHING DISABLED PEOPLE AND COMMUNICATION SYSTEMS

How then to investigate disabled people's exclusion from communication systems, and the use-value of those systems that are on offer? What does it mean 'to do empirical research in an unjust world' (Lather 1986: 257)? In recent years disability research has become a hotly contested topic, with academics accused of carrying out parasitic research at the expense of disabled people (Hunt 1981). These issues will be discussed alongside arguments for a new 'emancipatory' disability research paradigm. I will then describe my own methodology and data generation strategies, and my influence as a disabled researcher. Finally, I will briefly consider the generalisability of research conducted in such a rapidly changing communication environment.

EMANCIPATORY RESEARCH

It has long been argued that traditional research in the social sciences has mirrored and perpetuated the power relationships experienced by oppressed people in their day-to-day lives (Bourne 1980; Stanley and Wise 1993). Following in this tradition, research is often said to be an alienating experience for disabled research participants - it is something that is done to them over which they have little or no control (Oliver 1992). The main benefit of research into disability is often to the researcher and their academic record - it does little to improve the position of disabled people and may even compound their problems (Oliver 1990).

The shift away from the unquestioned dominance of the individual, medical model of disability has been accompanied by a shift in the way disability research is carried out. Disabled people have taken a lead from critical social science, feminism,

and majority world writers like Freire (1972), and have produced critiques of both positivist and interpretative research methodologies (Oliver 1990; 1992; Ward and Flynn 1994). A new 'emancipatory' research paradigm has been elaborated which now serves as an ideal towards which researchers working within a social model of disability can aspire - its aim - 'to make disability research more relevant to the lives of disabled people' (Oliver 1992: 109) and thus to make research part of the solution not part of the problem. The emancipatory paradigm then is concerned with:

the systematic demystification of the structures and processes which create disability and the establishment of a workable dialogue between the research community and disabled people in order to facilitate the latter's empowerment. (Barnes 1992a: 122)

This new paradigm is more a set of loosely defined principles than a set of rules for doing disability research (Zarb 1992). I will briefly explain some of these principles, whilst describing if and how they were incorporated into this project.

Theoretical assumptions

The initial question which any social researcher should ask themselves deals with ontological position: 'What is the nature of the phenomena or entities, or social 'reality' that I wish to investigate?' (Mason 1996: 11). Feminist researchers have produced an alternative to traditional 'Western Cartesian ontology' which deems women 'flawed, partial, lacking, different' (Stanley and Wise 1993: 199). Similarly, a core principle of an emancipatory research paradigm is said to be: 'the adoption of a social model of disability as the ontological... basis for research production'. (Priestley 1997: 91)

Much disability research has assumed an individualistic 'personal tragedy theory' of disability as its ontological base (Oliver 1996a: 131) and thus perpetuated the difficulties faced by disabled people. Hence Oliver calls for an alternative ontological position - political economy - which 'suggests that all phenomena (including social categories) are produced by the economic and social forces of capitalism itself' (Oliver 1996a: 131). This is of course implied by the social model, although not

strictly stated (Priestley 1998). Political economy is also advocated as a productive way to conceptualise the ageing process (Arber and Ginn 1991; Minkler and Estes 1991). Since technology, disability, and other dimensions of oppression are produced in this way, it is this ontological position which underpins the project.

The next question to which researchers are urged to address themselves is epistemological. According to Liz Stanley and Sue Wise (1993: 192) the question of epistemology is fundamental for feminism, since 'knowledge production is a crucial part of any apparatus of power'. They argue for a materialist theory of knowledge which is 'irrevocably rooted in women's concrete and diverse practical and everyday experiences of oppression'. This suggests that an epistemology of disability must be rooted in disabled people's experiences of oppression, should assume that disabled people are the experts about their own experiences, and that data can be generated by allowing them to describe these experiences. However, as described previously (see Chapter One), an epistemology for studying disability must be multi-level. Hence my analysis is not solely based on participants' individual experiences, but also on an extensive literature review.

Questions of ontology and epistemology are not merely theoretical but also intensely practical, affecting for example the questions asked of fieldwork participants (Abberley 1992). Since my work is grounded in political economy and the social model of disability, I therefore asked questions which located disability squarely in society.

Objectivity

In its attempts to ape the methodology of the natural sciences, social science has often aspired to objectivity in its research practises, and has championed the detached, independent, objective researcher. Feminist researchers have questioned this notion of objectivity as the one root to knowledge production, claiming for example that 'objectivity is a sexist notion that feminists should leave behind' (Stanley and Wise 1993: 59). Similarly, a core principle of emancipatory research is said to be: 'the

surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self emancipation' (Stone and Priestley 1999: 706).

In his critique of *A Life Apart* (Miller and Gwynne 1972), Paul Hunt (1981: 42) suggests that research can never be detached and impartial:

Faced with any socially oppressed group, social scientists have a choice of only two alternatives: either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practises... There is no middle way.

It is vital then for researchers to overtly serve the interests of disabled people in challenging their oppression. As a disabled researcher and activist, I found this unproblematic. However, since my ontological position leads me to consider disablist oppression an objective reality, I cannot support the notion that those involved in disability research should put aside any claims to objectivity (Stone and Priestley 1996; Zarb 1992). One *can* be objective about oppression, even whilst experiencing it oneself. As Hunt (1981: 43) suggests, it is 'precisely those who try to take a detached view of oppression who cannot be objective'. Like C. Wright Mills (1963: 11) then, 'I have tried to be objective, but I do not claim to be detached'.

Positive gain

Much disability research has been criticised for failing to have 'any serious effect on services for disabled people and their quality of life' (Oliver 1992: 109). The chief beneficiary of disability research is often said to be the researcher herself - a much-repeated mantra for which Finkelstein (1999: 863) has coined the term 'Oliver's gibe'. It would be easy to list what I might gain from my research with disabled people. What though of the participants in the research project and disabled people generally? An emancipatory paradigm *must* be based on reciprocity (Oliver 1992), therefore research participants must also gain in some way. So too should those disabled people who were not directly involved in the research. Hence we are urged 'only to undertake research where it will be of some practical benefit to the self empowerment of

disabled people and/or the removal of disabling barriers' (Stone and Priestley 1996: 706).

The findings of this research project will challenge many preconceptions about disabled people's relationship with communication systems. Through BT and other communication system providers, disabled people's requirements can be operationalised. Policy on accessibility and funding of communication for disabled people can also be affected. This study will also illuminate why such reformist solutions will not in themselves put an end to the disablement of people with impairments. At a more individual level, those disabled people who were directly involved with the research often thanked me for an enjoyable experience, and hopefully learned something from the process.

An important part of ensuring that disability research has benefits for disabled people is dissemination, a much-neglected area in the literature on social research (Roberts 1984). Good disability research does not end with data analysis. If research is to make changes, it must share knowledge and ideas with other disabled people, thus 'raising their consciousness, increasing solidarity and broadening the base of the disability movement' (Ward and Flynn 1994: 41). At the same time it must influence policy makers to make changes which will be of benefit to disabled people. It is vital then that these research findings are disseminated appropriately, in a variety of formats, since 'even good research is wasted if it does not reach those who need to be reached' (Ward and Flynn 1994: 44). At the time of writing, little has been done in terms of dissemination. It is intended though that the findings of this project will be disseminated not only to other academics, but also to disabled people and their organisations, telecommunications providers, and policy makers. A contact at the local council has agreed to assist with dissemination in the local area as soon as the thesis is completed.

Changing the relations of research production

Whatever methods are chosen to generate data, traditional social science research makes a firm distinction between the researcher and the research participants. The researcher is an 'expert', positioned 'in a knowledge hierarchy with - or rather *over* - those they research' (Stanley and Wise 1993: 7). Thus in much disability research, the research participants become simply 'the passive objects of the researchers investigations' (Abberley 1992: 141). Emancipatory research aims to reverse this hierarchy, so that those being researched become the experts and the researcher merely a facilitator. Hence those researching disability 'have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose' (Oliver 1992: 111). Extensive rapport building and the use of relatively unstructured interviews and focus groups to generate data were a step towards this goal. However, whilst the choice of what was discussed was to an extent in the control of the participants, this hardly constitutes a complete reversal of traditional research hierarchies. In emancipatory research it must be disabled people themselves 'who are controlling the research and deciding who should be involved and how' (Zarb 1992: 128). The decision to proceed was not made by the research participants, neither was the decision about how to proceed. The research agenda was in a very real sense 'reactive to the real agenda set by non-disabled people' (Finkelstein 1999: 862) who produce and control technological and social change.

Neither do the material relations of research production fit in with an emancipatory paradigm. It has been noted that neither researchers nor research participants have much control over the material relations of research production - 'it is not our hand that controls the light switch but that of funding institutions and policy makers' (Zarb 1992: 127). It is important to recognise the constraints this may pose. We may not for example be able to commit ourselves to serving only the interests of research participants, since 'we have to pay attention to the interests and priorities of funders and these will not always be the same thing at all' (Zarb 1992: 129).

This project was funded by the Economic and Social Research Council (ESRC) and British Telecom (BT). I am very aware of the potential pitfalls of trying to 'serve three masters' - disabled people and their organisations, academia and 'big business'.

Both academic funding bodies and privatised companies like BT are part of the system which produces disability. Hence at a structural level there are major conflicts of interest. Arguably, common interests do exist however. For example, if disabled people's communication needs are identified and fulfilled, both the consumers and the producers of the resulting systems will benefit. Emma Stone (1997: 218) highlights how the use of multiple partnerships in her research on disability in China made the research less emancipatory since 'the more powerful one partner, the less room there is for meaningful participation by less powerful partners'. There would however have been no possibility of her research leading to action without her links with officials and other agencies. Similarly, it seems possible that my research will be more likely to lead to positive change for disabled people because of my links with BT. It is important to note that whilst initially I was very uncomfortable about how much control BT would demand, their interference was minimal, and I was grateful that they let me 'do my own thing'.

STRATEGIES

Whilst this project cannot be described as textbook emancipatory research, I am committed to its goals, and did what I could to incorporate its principles. I therefore drew upon certain data generation strategies in order to make the project as responsive to participants' inputs as possible.

Action research is another problem solving approach to research practise. As with emancipatory research, there is a concern with praxis - 'purposive action (including political action) to alter the material and social world' (Jary and Jary 1995: 517) - such that 'the intention to effect social practice stands shoulder to shoulder with the intention to understand it' (Kemmis 1982: 17). Central to action research, is 'a self-reflective spiral of cycles of planning, acting, observing and reflecting' (Carr and Kemmis 1986: 162) allowing for modifications in the overall plan as the research progresses. This flexible approach to research production allows increased

involvement from research participants, and was further assisted by the decision to use qualitative methods of data generation.

Although there is 'no simple causal relation between the use of qualitative data and the removal of disabling barriers' (Stone and Priestley 1996: 705), most researchers working within a social model framework do not use formal structured interviews or questionnaires to generate data. Qualitative research allows more scope for participants to take control over their words, and thus affect the direction of the research (Shakespeare 1996a). As Janet Finch (1986: 194) asserts:

qualitative methods have great potential for involving research subjects in a collaborative way and thereby putting the means of change into participants' own hands. The research process itself in a sense becomes a means of empowering the powerless, by sharing with them the ability to reflect upon one's own position, to see one's circumstances as a product of social forces, to modify one's self image, or to identify points at which the means of social change lie within one's own grasp. (Finch 1986: 194)

Qualitative approaches to data collection offer greater flexibility than quantitative methods, allowing for changes in direction as the research progresses, are a good way of getting in depth first hand knowledge of the social world being studied, and are especially suitable for small scale studies such as this one (Finch 1986). Furthermore, they have been specifically recommended for research into the effects of new communication systems, since the issues of importance have not yet been clearly defined (Jouet and Coudray 1991). Hence I chose to use primarily qualitative methods of data collection, namely participant observation, focus group discussions and individual semi-structured interviews. I will now give a brief overview of the study:

THE STUDY: OVERVIEW

The study involved three phases of data generation, with each phase informing subsequent ones. These were not however, as initially planned, strictly sequential.

David Walsh (1998: 223) contends that much ethnography has loose phases and activities, giving it a funnel structure 'in which the research is progressively focused over time'. This was certainly the case with this research project. Phase one, spanning a period of around 14 months from November 1997, was a period of participant observation at a local resource centre for disabled people. Phase two involved four focus group discussions with disabled people, conducted between March and September of 1998. Phase three - in depth individual interviews with 22 disabled people - began in April 1998, and ended in January 1999. By the use of these three methods, I was able to gradually focus in on the topics of interest.

As suggested by Barnes (1992a), I had a preliminary meeting with all interview participants where I shared information about the purposes of the study - including what I stood to gain from the research, what the benefits of the research might be for disabled people, and how I intended to do the research. The focus groups however were more difficult to organise than anticipated so such a meeting was not always possible (see below). No pressure was placed on anyone to participate, and I made it very clear that should they decide to be involved, they could drop out whenever they choose. As well as enabling people to give properly informed consent, this initial meeting helped to break down any social barriers between myself and the potential participants. I felt it important to establish relationships with participants, especially since some would be involved in repeat interviews (Oakley 1981). Establishing a rapport with all those who were to be interviewed was however very time consuming, and time was not on my side.

After the actual data generation, I had intended that transcriptions of the individual interviews and summaries of the focus group discussions would be given to participants, which they would be encouraged to comment on, or change as they saw fit. These good intentions fell by the wayside however, as I found I had neither the time nor the resources to perform such member checks. To date I have only been able to fulfil this obligation to the first four people interviewed, and participants in one focus group. Of these, just one interview participant asked me to make alterations. Whilst they were happy about the accuracy of the transcription, they had made a number of personal comments about others which I was asked to delete.

Member checks are not generally viewed as a particularly reliable way of establishing the validity of data (Mason 1996; Schwandt 1997). Rather, they are the 'civil thing to do for those who have given their time and access to their lives' (Schwandt 1997: 89). This omission is on my conscience therefore, and is something I plan to rectify as soon as time allows with return visits to all research sites. I will now justify my sampling strategies and choice of methods.

THE SAMPLING FRAME

Resource centre users

As communication systems are often seen as effective tools to enable disabled people to live 'independently', I decided to focus on those disabled people living in the community, and exclude those forced to live in residential institutions from the sampling frame. I was also anxious to involve the often forgotten majority of the disabled population - older people and those outside paid employment. For these reasons, I decided to select the sample from local resource centres. There were disadvantages with this strategy however. Very few disabled black or minority ethnic people use such services, so with the exception of two Asian focus group participants, those involved in the research were exclusively white. Because of the role of the centres in providing services for those with physical impairments, there was no involvement from people with the label of learning difficulties or from any Deaf people (although several had hearing impairments). By contacting potential participants through resource centres, I also realise I did not reach the most isolated members of the disabled community - all obviously had some sort of social contact. Whilst it would have been desirable to fill these gaps, time constraints made this impossible.

Fieldwork was conducted at four resource centres - Airedale, Christy Brown, Colliers, and Stanmore Hill (names have been changed to protect the anonymity of participants). Whilst age restrictions are said to represent institutional ageism (Bytheway 1995), and Barnes (1990: 201) suggests that resource centre user status

'should not be dependent on age', all four centres limited their intake in this way, with Christy Brown and Colliers catering for those between the ages of 30 and 65, and Airedale and Stanmore Hill catering for 16 to 45 year olds. Colliers has the highest proportion of older users (around 40%), and for this reason, I chose to conduct the participant observation there. The manager was sympathetic to my plans, and following clearance from his line manager, I received the official go-ahead and began to immerse myself in the world of the resource centre. Some participant observation was also carried out at Stanmore Hill resource centre, where I was also made to feel very welcome by staff. Focus groups were conducted at all four centres, and interviews at both Colliers and Stanmore Hill.

City-on-Line (COL) participants

In my first meeting with the manager at Colliers, I learned about a pilot project being conducted in the local area - its aim: to demonstrate the power of Internet technology in improving disabled people's quality of life. The project was part of a larger enterprise, funded with European Union money, which was running in a number of European cities. It was well publicised through various media, and was undoubtedly a jewel in the local council's crown. After a lengthy period of selection, the project eventually provided just 18 local disabled people with a networked PC with video conferencing facilities. The package also included chat-line software, a local access guide, and an online shopping service in collaboration with a major supermarket. The participants were all outside employment, had a variety of physical impairments, and covered a broad spectrum of ages. They had a wide range of previous computer experience - some had never used a computer before, and some had completed a number of training courses. Two computers were also placed in Christy Brown and Stanmore Hill Resource centres, and following the 'voluntary' removal of two computers from participants, Colliers and Airedale also received equipment.

Obviously, I was keen to talk to participants on the project, as well as those who were involved in setting it up and running it. Hence I arranged meetings with Alastair, the co-ordinator of the project, and Isobel, a freelance development worker (not their

real names). Alastair was, at least initially, keen on my involvement, since no formal mechanism for evaluation of the project had been planned. He agreed to contact participants on my behalf regarding their willingness to talk to me. When contacting research participants through gatekeepers - 'the sponsors, officials and significant others who have the power to grant or block access' (Walsh, 1998: 221) - it is difficult to be sure how recruitment strategies are conducted and prioritised. Eventually, only Martyn, Kate, John and Kathleen were accessed through Alastair, leaving me unsure as to whether other participants had actually been contacted.

I was able to talk to more participants however. Kathleen put me in touch with Edith. I was given Bill's contact details by the manager of Airedale resource centre, and I already knew Hugh and Curtis from Colliers Resource Centre. Hence eight of the eventual interview participants were part of the COL project. I had also hoped to conduct a focus group with participants, but received little enthusiasm from them. I would have been very interested in following up the project in more depth through interviews with those professionals who were instrumental in its conception. Ultimately however, there seemed to be a certain lack of trust from the project co-ordinator, which would have made this course of action problematic. He was perhaps right to distrust me. This kind of research would however be vital in formulating theory about emancipatory technological provision, since, to paraphrase Jenny Bourne (1980: 339), 'it [is] not [disabled] people who should be examined, but [non-disabled] society'.

What about the workers?

As the research progressed I became concerned that in limiting my study exclusively to those people who were outside employment, I might miss out on valuable data and perhaps underplay the benefits of communication systems. Helen and Max, who were accessed through resource centres, were attached to these centres as workers, as were some participants in focus group three. I also began to follow up my own contacts in order to rectify this imbalance, although only Jessica was eventually accessed in this way. Whilst it would have been desirable to include the perspective of more waged

disabled people, I realised that employment was an area which was being addressed with regard to ICTs (eg: Jolly 2000; Roulstone 1998a), and that I could more usefully focus elsewhere.

PARTICIPANT OBSERVATION

Participant observation is a method which 'encourages researchers to immerse themselves in the day-to-day activities of the people whom they are attempting to understand' (May 1997: 133). One of its most positive aspects is that 'it is less likely to lead researchers to impose their own reality on the social world they seek to understand' (May 1997: 137-138). Prior to undertaking the fieldwork, whilst I had read books about segregated day care provision, I had never actually set foot in such an establishment. I undoubtedly held many assumptions about resource centres as bleak, dumping grounds for society's unloved and unwanted. What I found at Colliers was a group of warm, witty, sociable people who obviously gained much from their use of the centre. Furthermore, the fact that I became 'part of the furniture' for many of those who were eventually interviewed, was vital in establishing rapport, and went some way towards equalising the hierarchical relationship between researcher and researched.

My role at Colliers resource centre where participant observation was carried out was similar to that of voluntary worker (VW) described by Barnes (1990). I was neither staff nor user, neither fish nor fowl. Both groups took me into their confidence however. My presence was not seen to be unusual, as students often pass through the centres hoping to gain work experience. Whilst little was expected of me in terms of practical assistance, I was sometimes called upon to assist with basic tasks - helping people to the toilet, fetching cups of tea and so on. For the most part however, I was able to spend my time chatting with users and getting to know them. Consequently, subsequent interviews were less formal and more conversational in character.

It is interesting to compare my reception at Colliers from that I received at Stanmore Hill, which I visited on just five or six occasions. My relationship with research participants here felt much more hierarchical. I had visited the centre long before the fieldwork commenced to lead a discussion on eugenics, so I felt I was already perceived as an 'expert'. I also had close links with Kenneth, the Internet-enthusiast staff member who I had met some time before when he was covering for absent male staff at Colliers. Kenneth was very interested in my research, and did his utmost to help as much as he could. This may however have had an adverse effect in terms of establishing rapport with users. He was keen to introduce me to any users who had shown an interest in using the Internet, giving the impression that I had a special interest in them alone. Furthermore, after my first fieldwork visit to the centre, Kenneth downloaded a picture from the Internet - me playing in a band - which I was alarmed to see on the wall on my next visit. This probably did little to increase rapport with the centre users, but did seem to increase my status as a minor celebrity. There may be other reasons for the increased reticence of participants accessed at Stanmore Hill, and the awe with which they seemed to regard me. They were younger than the Colliers participants, had often been disabled from a younger age, and were exclusively male.

I felt the period of participant observation was a vital springboard for later phases of the fieldwork. It provided valuable insights into the nature of resource centres, taught me much about the lives and aspirations of those who used them, and suggested many ways in which technology might assist or hamper them in their day-to-day lives. It also taught me much about the nature and influence of the COL project. However, using participant observation alone, it could have taken years of research to produce a meaningful amount of data about disabled people's communication system usage. Focus groups were the next step towards this goal, as will now be considered.

THE FOCUS GROUPS

Broadly speaking, focus groups are simply 'a research technique that collects data through group interaction on a topic determined by the researcher' (Morgan 1996, cited Morgan 1997: 6). As such, they offer a compromise between the strengths of participant observation and those of individual interviewing, yet give access to forms of data which cannot be easily obtained using either of these methods (Morgan 1997). They yielded for example an incredibly broad range of data about communication systems. Since it is hard to predict which use-values will become the most important in the future, this kind of breadth is suggested as one way of maximising the generalisability of research into communication systems (Schofield 1992). Focus groups are then a useful tool when studying the cutting edge of technology. What though can they offer to disability research? Their main advantages and disadvantages are discussed below:

Focus groups and disability research

A particular strength of focus groups is said to be the ability to 'turn the interaction in the interview over to the participants themselves' (Morgan 1997: 11), thus giving participants more control over the direction of the research. Their potential as a radical technique 'to fuse social research and social change' (Johnson 1996: 519) is also highlighted. Alan Johnson (1996: 517) claims that the focus group can be 'a "transformational act", raising consciousness, and empowering participants, rupturing rather than reproducing underlying relations of exploitation and domination'. Furthermore, they can foster a collective identity among participants, transcending individualism and connecting up individual narratives 'first to each other, and then to wider social economic, cultural and political influences' (Johnson 1996: 534). The focus groups certainly provided a useful setting for participants to exchange information with each other, as this extract from focus group one (fg1) demonstrates:

Doris

I sleep downstairs and my husband sleeps upstairs, and I've got a...

Maureen

Intercom?

Doris

Intercom! And I have t' phone from his bedroom to me. And if I need him, I just press a button and he can talk to me.

Marge

Ah, very good. Very good. Where d'you get that?... Where d'you get them from Doris?

Doris

Comet

Maureen

Same place as I got mine Doris!

(fg1)

Also, as Caroline told me at the end of focus group three (fg3), they allowed participants to connect their own narratives with those of others:

Caroline/fg3

It was interesting finding out how other people find the same things, because you think it's just you!

Since focus groups are a relatively non-hierarchical method, and a contextual method which does not focus on individuals devoid of social context, it is suggested that they offer two key features which are an essential part of feminist enquiry (Wilkinson 1999). It seems that focus group discussions can also be an invaluable part of an emancipatory paradigm for disability research, and may 'substantially enhance the collective and participatory content' of that research (Stone and Priestley 1996: 711). Little published research has actually used the method with non-

impairment-specific groups of disabled people however, possibly because of anticipated practical difficulties.

Jenny Kitzinger (1994: 112) for example claims that group work is invaluable when working with people 'who share stigmatised or "taboo" experiences', yet seems hesitant about their use with disabled people. Because of the reliance of focus groups on verbal interaction, she suggests that group work can discriminate against people with communication impairments. Furthermore, she proposes that if each group member had a different impairment this could 'compound each of their communication difficulties'. Whilst I encountered few of the difficulties described by Kitzinger, not everybody is equally comfortable speaking in public whatever their impairment. This certainly proved true in all four focus groups. Whilst some enjoyed 'performing' for each other (Jarrett 1993), others were more taciturn. There was a difficult balance then between eliciting some response from quieter members, and not creating unnecessary anxiety for them. On the whole, I was inclined not to push people to speak if I felt this would cause discomfort. The additional use of individual interviews in this study helped to minimise these kinds of difficulty. Those who were unable to express their views in a group setting had the opportunity to do so on a one-to-one basis. The use of individual interviews in this study had other benefits. Because of environmental barriers and inadequate transport, many disabled people find it difficult to travel to a central point for a group interview. Whilst all four focus groups were conducted in resource centres, so that a special 'trip out' was not usually necessary, participants in the COL project rejected my proposal for a focus group because of such logistical problems.

Setting up the focus groups

Having received the official go-ahead, and acquainted myself with the workings of the resource centre, the next step was to select the focus group participants. Random sampling is thought inappropriate for focus group research because of the small number of participants usually involved in such projects, and because randomly selected groups are 'unlikely to hold a shared perspective on the research topic and

may not even be able to generate meaningful discussions' (Morgan 1997: 35). Purposive or theoretical sampling techniques then seemed most appropriate (Glaser and Strauss 1967; Patton 1990). In the event, however, I had little control over who participated in the focus groups. Naively, I had imagined that they would be easily organised. Not so! Arranging anything at a resource centre is fraught with difficulties. Because of the various groups that were run throughout the day, the canteen lunches, the ubiquitous afternoon bingo sessions, the trips out, and the constant problems with transport, many users had quite hectic timetables. Whilst it was relatively simple to arrange individual interviews around these constraints, focus groups were another matter.

In the end, although it was not the ideal solution, I used alternative recruitment strategies. At two of the centres, with the permission of staff, I was able to hijack an already established group. At Colliers, this was the extremely popular 'Memory Lane' discussion group, a space for older users to reminisce about times gone by. At Christy Brown I talked with the Access group. In both instances, I was unable to talk to participants before the event, something I would prefer to have done. At Colliers, staff suggested I run the focus group only the day before the event, because of the absence of the usual group leader. At Christy Brown, although the focus group was arranged well in advance, staff had not passed information about the project to the focus group participants as promised. Both of these groups mainly consisted of non-IT users. At the other two centres, I was assisted by enthusiastic staff, who selected likely participants on my behalf on the basis of their computer knowledge. At Stanmore Hill, a group of four men, all familiar with computers was gathered. At Airedale, the manager recruited six IT users, some of them users of the centre, and others staff. Both of these latter groups were informed about the project in advance.

Morgan (1997) suggests an ideal group size of between six and ten, since it may be difficult to sustain a discussion with fewer people, and difficult to control one with more. Whilst I had planned to follow this advice, because of my eventual lack of control over focus group recruitment, only two of the focus groups fell within these limits. His warning proved accurate! He also proposes that 3-5 groups are usually the optimum number, with more groups seldom providing any new insights. Here at least

I was able to stick to my plans. Figure 1 shows the locations, dates and make-up of the four focus groups.

Figure 1: Focus groups

	<i>Location</i>	<i>Date</i>	<i>Number of participants</i>	<i>Number of men</i>	<i>Number of women</i>
<i>Fg1</i>	Colliers	12/03/98	11	3	8
<i>Fg2</i>	Stanmore Hill	17/07/98	4	4	0
<i>Fg3</i>	Airedale	29/07/98	6	2	4
<i>Fg4*</i>	Christy Brown	09/09/98	8	2	6
			29	11	18

* *One woman and one man were present for only part of the discussion. This group also included a female staff member.*

Conducting the focus groups

Traditionally, focus groups have relied on a fairly structured interview and have thus required a high degree of moderator involvement to keep the discussion on track (Morgan 1997). An alternative approach is possible however, where unstructured questioning is used and the interviewer only asks questions or probes to keep the discussion going. This latter approach is said to be especially suitable for exploratory groups, allowing more flexibility of response (Frey and Fontana 1993). Low researcher involvement is also said to be essential if 'synergy' is to take place: a lively group discussion where participants talk not just to the researcher, but create 'rich and meaningful multilateral conversations between themselves' (Johnson 1996: 522-3). Hence a relatively unstructured interview with low moderator involvement seemed most appropriate.

No personal data relating to age, living arrangements and so forth was requested of participants in the focus groups, since I anticipated that such questioning might be inappropriate in a group setting. Instead, I gave a brief description of my interest in the area, asked all participants to introduce themselves and say a little about the communication systems they used, then let them voice their opinions on the subject. Prompting was inevitably necessary, sometimes to keep the conversation going or, more often, to keep the discussion on the topic. The discussions were led around the following main topic areas:

- Currently used communication systems: benefits, drawbacks and barriers
- Other communication systems: benefits, drawbacks, barriers
- The future: hopes, fears, what do disabled people really need?

The focus groups enabled me to learn the phraseology that the participants use to describe their experiences of communication systems, as well as establishing the issues that they thought particularly important. This was of great benefit when devising an appropriate interview schedule which would provide 'depth and detail' on topics discussed more broadly in the focus groups (Morgan 1997: 23). The individual interviews will now be considered:

THE INDIVIDUAL INTERVIEWS

In qualitative research interviews, data is generated via the interaction between the interviewer and the interviewee. Robert Burgess (1984: 102) refers to qualitative interviews as 'conversations with a purpose' and Jennifer Mason (1996: 38) agrees that they are characterised by an informal style, often with the appearance of a conversation rather than a 'formal question and answer format'. The researcher does not therefore have a structured list of questions to be answered, but a list of topics which she wishes to cover in the interview. It is not then a conversation between

equal partners. The researcher 'defines and controls the situation' (Kvale 1996: 6) and as a rule, the interviewee has a relatively passive role in the process (Oakley 1981).

It was intended that the interviewees in phase 3 of the project would be largely drawn from the participants in the group interviews and would therefore have been involved in defining the themes which would then be discussed in more depth. Their role would not then have been an entirely passive one, although the social relations of the research process would not have been completely overturned. Whilst all focus group participants were asked about their willingness to be interviewed individually, only 5 of the 29 people who took part in focus groups were involved in repeat interviews. Other interview participants were accessed through contacts I had made conducting participant observation, through the COL project, and, in one instance through my own network of friends (see figure 2).

Setting up the interviews

All of those interviewed at their resource centre knew me already, and those who did know me in this capacity were visited in their homes prior to the interview, or, in one instance, in respite care. Participants were encouraged to ask me questions should they so wish, both about my own experiences, and about communication systems. Hence I was sometimes called upon to give impromptu IT training - something I had not expected. Edith's computer training from the COL project had been negligible (see Chapter Five), and I spent considerable time showing her the basics - how to open a word file, how to print letters and so on. I also pruned a bush in her garden which was preventing her from going along her garden path in her wheelchair. Although I was pleased to help Edith out, and to feel that perhaps I was giving *something* back, I left her house furious that she was so obviously not receiving the support she required.

The eight interviews conducted in people's homes were in a way the most satisfying. There were fewer interruptions (unruly puppies and parrots aside). I was touched by the way that people welcomed me into their homes, and I inevitably stayed much longer than I anticipated - sometimes for over five hours. The average

length of taped interviews conducted in this way was approximately 88 minutes, although this masks a wide variation. John's interview for example took considerably longer than the tape suggested as I was requested to switch off the machine whilst he composed his comments on his Lightwriter (a portable communication device). This was an exhausting process for him, so the interview was eventually conducted over two days. Other interviews filled two hours of tape, and could have continued for longer had I not lost concentration and drawn them to a close. On just one occasion, I arrived home to find that my microphone batteries had run down, and nothing had recorded. I did my best to reconstruct events from notes I had taken.

I think it was refreshing - unusual even - for some of the participants to have such interest shown in their opinions, and I *think* they enjoyed my company. Kathleen sent me the following e-mail after my first visit to her house:

Hi Alison

Thanks for yesterday, it was a great day for a chin wag! Even if I did all the talking, it was super having someone with a different outlook. I really enjoyed your company and I look forward to our next meeting. I promise not to talk too much, and only answer your questions. Don't let anyone hear my awful Yorkshire accent!

Love from Kathleen.

I too enjoyed the time I spent with Kathleen and the others. It is then a matter of deep regret that I was unable to keep up these new friendships, having had a serious multiple sclerosis (MS) relapse which began only a day after the end of the fieldwork.

In contrast to those interviews carried out in people's homes, those conducted at resource centres tended to be shorter, and less relaxed. People were often anxious about being late for their transport home or missing activities like swimming trips. The average length of these taped interviews was approximately 60 minutes. Those who were interviewed tended to be self-selecting, since many had no interest in talking about communication systems.

Interestingly, I found it much easier to interest female resource centre users in participating. This could be due to my own status as a woman, or a consequence of men's supposed relationship with science and technology. Scherer (1993: 132) suggests that non-technologically minded men may feel particularly threatened by technology 'because they lack skills that are traditionally male objects of interest'. Hence whilst computer-literate men were keen to talk to me, those who were not seemed reluctant to show their ignorance. Cedric for example admitted that modern technology made him feel inadequate, but could not be persuaded to tell me more about this in an interview. Disabled women however are subject to different expectations (Fine and Asch 1988), and would more readily admit their technological illiteracy to another woman in an interview situation (see Chapter Five). Finally however, I managed to interview equal numbers of men and women. The women tended to be older than the men with a mean age of 53.5 compared to 45.4 for the male participants. Half of those interviewed were over the age of 50 - 4 men and 7 women, and 23% - 1 man and 4 women - were aged 65 and above. *Figure 2* shows locations and dates of interviews, ages of participants and how they were accessed. All names have been changed to protect the anonymity of the participants.

Figure 2: Interview participants

<i>Date</i>	<i>Name</i>	<i>Age</i>	<i>Interview location</i>	<i>Accessed via</i>
<i>MEN</i>				
19/05/98	Martyn	50	Home	COL
26-27/05/98	John	38	Home	COL
20/09/98	Andrew	37	Stanmore Hill	PO
20/09/98	Neil	37	Stanmore Hill	FG2
21/09/98	Bill	29	Home	COL
09/10/98	Peter	24	Stanmore Hill	FG2
03/11/98	Patrick	59	Colliers	FG1
03/11/98	Frank	77	Colliers	FG1

<i>Date</i>	<i>Name</i>	<i>Age</i>	<i>Interview location</i>	<i>Accessed via</i>
17/11/98	Hugh	52	Colliers	PO/COL
12/01/99	Curtis	47	Colliers	PO/COL
12/01/99	Max	49	Colliers	PO
		(Mean = 45.4)		
<i>WOMEN</i>				
04/06/98	Kate	35	Home	COL
14/09/98	Edith	74	Home	COL
30/09/98	Helen	32	Home	FG3
20/10/98	Jessica	29	Home	PC
06/11/98	April	55	Colliers	PO
13/11/98	Dot	61	Colliers	PO
13/11/98	Agnes	74	Colliers	PO
17/11/98*	Maude	78	Colliers	PO
	Nancy	67		
05/01/99	Danielle	28	Colliers	PO
06/01/99	Kathleen	55	Home	COL
		(Mean = 53.5)		

Key:*COL: City-on-Line**FG: Focus Group**PC: Personal Contact**PO: Participant observation*

- * *Maude and Nancy requested a joint interview. This had many of the strengths of the focus group, whilst still allowing the depth of questioning possible in an individual interview.*

Interview schedules

The interview schedules covered broadly the same ground as the focus group schedules (see above), since these had proved successful in generating suitable data. The interviews however allowed me to fill in the details which were lacking in the focus groups. Even in the individual interviews however, I was reticent about asking what I saw as 'personal' questions about for example income levels. Since the participants' knowledge and usage of technology varied widely, the schedule had to be flexible. Participants in the COL project for example were asked specific questions about their experiences on the project. In all cases though, the interview followed the same broad topic areas:

- Personal details:
Age, length of disablement, living arrangements, social contact/getting out, educational history, employment history, etc
- Communication systems:
What equipment, ease of use, use value, information provision and knowledge of other equipment, perceived use-value of other equipment, satisfaction with service, comparison with other communication media, etc
- Usage of communication systems:
What is it used for, luxury or necessity, importance for disabled people, etc
- Information technology:
Have you used IT, why/why not, barriers, training, pressure to learn, use-value, etc
- Internet:
Knowledge of Internet, use-value: shopping, information, communication, etc
- The future:
Hopes and fears, getting left behind, need for technology, other needs, etc
- Any other thoughts...

With participants' permission, all interviews and focus groups were recorded using a Dictaphone. They were then transcribed and coded. Coding was cross-

sectional, since I wanted to be able to 'locate and retrieve issues, topics, information, examples and themes which (did) not appear in an orderly or sequential manner in the data' (Mason 1996: 113). This was done manually, rather than using one of the many computer packages now available, despite the fact that the use of computers 'can help to develop more refined coding schemes' (Seale and Kelly 1998: 156). On reflection, this decision was taken largely because, like many of the research participants, I did not perceive the use-value of such a system to merit the time and effort needed to utilise it effectively (see Chapter Five). Having described the nuts and bolts of the operation, it is perhaps appropriate to say a few 'reflexive' words about my influence and experiences as a 'non-detached' disabled researcher.

THE INFLUENCE OF THE DISABLED RESEARCHER

Had I not become disabled in my early twenties, my life would undoubtedly have taken a different course. My political education would not have been such a priority, and I would certainly not have become involved in disability research. Whilst I do not choose to join 'the true confessions brigade' (Barnes 1998: 146) by including a lengthy personal biography, it would be wrong to ignore something that had such an effect on the research process. I will then briefly consider the implications of my disabled status firstly for my relationship with the research participants, and secondly, on the actual process of research production.

It is suggested that when a woman interviews another woman 'both parties share a subordinate structural position by virtue of their gender. This creates the possibility that a certain kind of identification will develop' (Finch 1984: 76). Whilst this *possibility* may exist, Anne-Marie Fortier (1998: 54) contends that her gender did not 'dissolve the distance' between herself and the women she was studying. It is difficult then to support the claim that reciprocity is 'an inevitable result of an "insider" researching the lived experiences of the group to which she belongs: through the mutual exploration of the research topic which is of common concern to them both' (Vernon 1997: 169-170). Inevitably there will be class antagonisms within any

oppressed community (Callinicos 1993), something which such assumptions appear to mask. This may be particularly marked between researcher and researched, particularly in a project such as this where the majority of participants were not in employment, and had not had access to many educational opportunities. Furthermore, the majority of the participants were older than me, and obviously saw me as a 'slip of a girl'. As Maude commented: 'You're nowt but a bairn!'

Class and age differences aside, my status as a disabled person definitely made a difference to the research participants. My impairments fluctuate and are not always immediately obvious to others, hence self-disclosure was usually necessary. I was therefore able to gauge responses 'before' and 'after'. I usually sensed that participants became less guarded and more open in their responses when they realised that we *did* have something in common. Kate shared my impairment, and we bonded over our shared liking for one local neurologist, and our dislike of the other. For others like Max, identification occurred in terms of our shared oppression rather than our shared impairment status. He recounted an unpleasant experience of direct discrimination, then asked me: 'I mean, you've been there yourself haven't you? It's a battle isn't it to keep going and doing stuff? And people say things and knock you back sometimes'. The PhD process was certainly a battle, as will now be considered.

Uncertainty has been a major feature of my life since acquiring an unruly impairment. Inflexibility creates problems. Chapter Two discussed the lack of flexibility in the commodity labour market as a major feature of the disablement process. Disability research is no different. As Oliver and Barnes (1997: 812) contend,

for some disabled workers everyday tasks take longer. Some people with intermittent and unpredictable impairments such as multiple sclerosis for example, may need a more flexible and less demanding work schedule.

I found the demands of the PhD process both inflexible and demanding. I also encountered 'unforeseen problems relating to periods of sick leave' (Zarb 1997: 62), so that my work was interrupted on more than one occasion. Whilst a doctor's note will ensure some flexibility in terms of time, money is a different matter. Whilst BT

were financially flexible and allowed me an extra six months funding to cover for illness, I was requested to return cheques to the ESRC until such time as I was able to return to my studies. The end results of this inflexibility were that my fieldwork was cut short, and I was unable to fulfil certain obligations to research participants within a reasonable time-scale, making the project less 'emancipatory' than it otherwise might have been. I am also significantly poorer now than when I began. This situation must be challenged as a matter of urgency if more disabled people are to be encouraged to enter the research arena.

I am very aware that any research into the social implications of rapidly changing technology could quickly become outdated. Hence before presenting the findings of the study, I will briefly consider their generalisability.

FROM PARTICULAR TO GENERAL

This was a small scale study, which set out not only to document the present, but also to inform future developments. How generalisable can its findings be? Whilst the sample was selected in part *for* their typicality, I quickly discovered that they were atypical in certain key respects. They all had at least some knowledge of ICTs because of their links with COL project participants, many of whom were resource centre users themselves. As Lil told me: 'I'd never even heard of an e-mail before Kathleen went on City-on-Line!' The influence of the COL project was far reaching, and even those with no direct involvement were touched by its presence. They were not then the naïve participants I had imagined they would be. Rather than limiting the generalisability of the findings however, this was undoubtedly a strength. It has been pointed out that:

Changes in both microcomputer technology and in individuals' level of experience with computers has been so rapid in the past decade that a study of what is today could arguably be a study of primarily historical interest by the time it gets conducted, written, and published. (Schofield 1992: 214)

Janet Ward Schofield's research had hopes not just of 'documenting the present, which is rapidly becoming the past, but of speaking to the future' (1992: 214). Hence she advocates studying *what may be*, by designing studies 'so that their fit with future trends and issues is maximised' (p. 221). By conducting the research in a non-typical technologically precocious site, I was able to study situations and experiences more likely to become common in the future. Hopefully, this will make the research more relevant and more generalisable by the time it reaches the public realm.

SUMMARY

Despite the fact that this project does not fit the model of emancipatory research - it is not funded by organisations of disabled people, neither did they formulate the initial research proposal or decide how the research should proceed - I did attempt to incorporate some of its principles. Intent 'is no guarantee of outcome' however (Barton 1996: 6) and as Oliver (1997: 25) rightly points out 'research can only be judged emancipatory after the event'. Hence, my success in producing a piece of research which has the potential to improve disabled people's lives has still to be tested.

The fieldwork confirmed that many disabled people are unable to access the technology which society has developed - technology which could potentially alleviate their disadvantage. This lack of access has profound implications for their inclusion/exclusion in twenty first century society, and must therefore be remedied as a matter of urgency. Drawing on the experiences and opinions of the fieldwork participants, the next chapter will examine the role which the current communications marketplace plays in perpetuating this lack of access, and suggest possible ways forward.

CHAPTER FOUR: CORPORATIONS AND TECHNOLOGICAL ACCESS

The disabled people who took part in the study all had some kind of telephone equipment in their homes, and despite the difficulties that some experienced using their equipment, all were adamant that it was a necessity. They were largely in agreement that access to IT equipment was becoming equally important, was often problematic, and that information and communication systems should be more readily available for disabled people who could benefit from their use. This was true even amongst those who were not enthusiastic about using such equipment themselves. They identified various barriers which they saw as making access more difficult, sometimes laying blame with manufacturers, and sometimes elsewhere. This chapter will assess the current business solutions to addressing the unmet needs of disabled people, and highlight ways in which accessibility can be further assisted.

As Amory Starr (2000: vii) suggests: 'Corporations now have global rights. People still do not'. In the global informational economy, the corporation is king. The right to free trade, enforced by international agencies such as the World Trade Organisation (WTO) and the World Bank (WB) is said to be 'one of the most significant components of globalization', and factors such as deregulation and privatisation have effectively handed 'the economy over to multinational corporations' (Starr 2000: ix). In the UK the telecommunications industry was the first to tread this path, a path not laid with disabled people in mind. The implications of this will be considered. An examination of corporate rhetoric around universal design, user involvement and information provision will then follow.

MARKET FORCES / DISABLING FORCES?

Caroline/fg3

In a sense there's gonna be a new class or whatever, or an extension of the old class system - people who have access to information technology and people who don't. They do a lot of talking about that, but I'm not aware of them actually doing anything about it other than talking about putting a few computers in schools. No doubt they'll be thinking of a nice term for it as well! ... I think that's not just an issue for disabled people, it's an issue for the whole of society isn't it?

Helen

I mean it could almost ... create a two tier or a two class society - those who use computers and those who don't - which is really quite dangerous. In a way it is a barrier as well as a means of access. It's both at once.

Traditionally many disabled people have been totally excluded from using telecommunications. Since the 1980's there have been massive changes in the way telephone products and services are delivered, which have influenced this exclusion. In the UK in the days before the Thatcher government, the General Post Office (GPO) had sole responsibility for providing both telecommunications and postal services. In 1969, the Post Office Act formally established the GPO as a statutory corporation headed by a government appointed chairperson (OFTEL 1998). There was little choice in the telephone equipment that was available, and the only information available for disabled customers was apparently a four page Post Office leaflet, *Aids for the Handicapped* (BT 1996). From having a state run monopoly, the UK now has over three hundred licensed companies providing telecommunications networks and services (OFTEL 2001). Whereas all telephones were once rented from BT, hundreds of models can now be purchased in any high street: 'fixed, cordless or mobile, analogue or digital - from different manufacturers and different service providers' (Ricability 1999: 2). At first glance, this might seem like a positive move forward for disabled people, enabling increased choice and hence increased

autonomy. However, as Doyal and Gough (1991: 66) suggest, not all choice has this effect: 'The choice of a brand of soap powder which is really no different from all of the others has more to do with a diminution of autonomy than its expansion'. Moreover, viewed within the wider context of mass privatisation, it seems that such choice might come at a price. As Starr (2000: viii) maintains, 'Much of what is defended in the name of consumers actually serves corporations'.

Privatisation has been described as one of the key trends of the second half of the twentieth century (Chapman 1990). Encompassing the 'sale of public assets, the introduction of competitive tendering, deregulation, and the establishment of surrogate markets within public sector organisations' (Jackson and Price 1994: viii), privatisation was a cornerstone of the Conservative Government's programme - a programme which New Labour has done nothing to dismantle. While profits from the now privately owned utilities go to the new shareholders, the gap between rich and poor widens yet further (Scase 1992). Unsurprisingly then, disabled and older people have not fared well from this rolling back of the state. Market-driven approaches to education have done nothing to secure the inclusion of disabled children in mainstream schools (Barton 1995; Norwich 1994). The selling off of local authority housing has compounded the shortage of accessible housing (Barnes 1991). Market-led policies have meant the complete disappearance of some transport services in favour of more profitable routes (Weyman-Jones 1994); and deregulation has also resulted in 'the proliferation of smaller buses', which often create yet more access problems for disabled people, having steeper steps and narrower aisles than what came before (Barnes 1991: 164). Finally, as Jay Ginn (1993: 32) comments, the systematic erosion of state pensions and promotion of private pension schemes is likely to have an adverse effect on many older people, particularly older women, and the privatisation of services will bear hardest on those older people who lack their own resources.

It seems then that there is indeed an 'essential contradiction between social progress and corporate profits' (Brook and Boal 1995: xi), and that the global trend towards privatisation and deregulation has done little to ensure a better quality of life for the worst off of the world. The telecommunications industry is no different.

Pamela Ransom (1994: 172) suggests that 'the marketplace alone will not produce accessible telecommunications equipment and services'. What then has the privatisation of telecommunications meant for disabled people in Britain?

THE PRIVATISATION OF TELECOMMUNICATIONS

In the early days of the Thatcher government, the GPO was separated into two separate organisations, one for the postal service and one for telecommunications. So British Telecom (BT) came into being. Then began the attack on BT's state monopoly, and calls for the liberalisation and de-regulation of the telecommunications industry. The Telecommunications Act (1984) was passed to license the soon to be privatised BT, and to provide a framework for promoting competition, and BT became the first publicly owned company to be sold off into private ownership and control, in an exercise Harold Macmillan famously described as 'selling off the family silver' (Chapman 1990).

According to one commentator, '(t)he principal question before and after privatisation is (and still is) how to prevent British Telecom from using its dominant market position to exploit customers.' (Newman 1986: 17). In an attempt to pre-empt such concerns, The Telecommunications Act (1984) deemed that a regulatory body was necessary to act as watchdog for the newly deregulated telecommunications industry. Hence the Office of Telecommunications (OFTEL), was established in 1984 to monitor the new licenses which the Department of Trade and Industry (DTI) would issue. The Director General of OFTEL, along with the secretary of state for Trade and Industry, has certain duties to disabled and older people which are enshrined in the Act. Section 3 (2) outlines the obligation

to promote the interests of consumers, purchasers and other users in the United Kingdom (including, in particular, those who are disabled or of pensionable age) in respect of the prices charged for, and the quality and variety of, telecommunication services provided and telecommunication apparatus supplied. (HMSO 1984: 3)

Also set up under section 54 (1) of the Telecommunications Act 1984, was the *Advisory Committee on Telecommunications for Disabled and Elderly people* (DIEL) which advises OFTEL 'on the particular interests and needs of consumers who happen to be disabled or elderly or both' (DIEL 2001: 1).

DIEL however is acting as advisor to a body with little power, since the Telecommunications Act 1984 created a 'somewhat lax regulatory structure' (Newman 1986: 171). Whilst OFTEL can handle complaints, make recommendations, and issue warnings to telecoms companies not meeting their license obligations, it does not have the power to shut them down (Chapman 1990). It is 'lacking in both sanctions and resources' (Newman 1986: 172). As one commentator concludes, 'OFTEL needs more powers, and it needs to spread its concern beyond the commercial and the economic to those of the telephone user.' (Chapman 1990: 192). Despite these shortcomings, OFTEL has managed to ensure that certain conditions are met by companies. It has done this by imposing license conditions on some operators, including BT, which require them to fulfil certain requirements with regard to disabled and older customers. However, where OFTEL feels that any company is already fulfilling its criteria, it does not take steps to amend their license (OFTEL 1998).

It seems that OFTEL's efforts may not be sufficient. Shortly after the BT privatisation, Age Concern published a report examining its effects on disabled and older people. According to their report, published in July 1987:

Since British Telecom was privatized in 1984, there has been widespread concern about the effect of its policies on poorer consumers, particularly elderly customers. Elderly and disabled customers have become worse off since privatization in virtually every aspect of telecommunication services. (cited Chapman 1990: 100)

Anticipating such concerns, BT had already set up a special unit - 'BT Action in the Interest of the Disabled' - which was to become the current BT Age and Disability Unit. Also in 1984, the company began to set up consumer liaison panels - mechanisms through which telephone users could have an input into future

developments. The first age and disability liaison panel followed in 1996 - a group of fourteen disabled people who meet regularly to give feedback to BT about their products and services (BT 1996). As will be discussed below, this burgeoning interest in user involvement was not something that the research participants were aware of, although several highlighted the need for such activities.

As already discussed, the push towards privatisation in telecommunications is not just a British phenomenon. Patrick Roe (1995: 3) expresses concern at the current 'worldwide trend towards liberalization and deregulation of the telecommunications industry', and predicts that within this environment of increased competition, there is a danger that industry will concentrate on what are seen as 'the more lucrative parts of the market'. Others are equally pessimistic, claiming that 're-regulation' may be necessary in order to 'protect underprivileged citizens' (Lindstrom and McEwan 1991: 450).

THE MOTIVATIONS OF PRIVATIZED COMPANIES

The new telecommunications environment for disabled people then, is ruled by market forces, and, in the absence of a regulator with teeth, is often reliant on the benevolence of operators. As described above, access to communication systems is viewed by the various operators as a problem to be solved through research into, and development of equipment and services that are physically accessible for those with particular impairments. In the case of BT, the impetus for this development work is described as a convergence of marketing and altruism:

At the end of the day, it's all about getting everybody onto the network. We're helping the company generate phone calls. We're extending the use of the telephone. We help people use phones who didn't know they had the ability. (BT 1996: 75)

The private sector's discovery of disabled and older people has both positive and problematic implications. Whilst it would undoubtedly be of benefit to find out what

these groups actually want, in the attempt to exploit new markets, companies may create 'needs and concerns that didn't exist previously' (Minkler 1991: 88).

Wolf Wolfensberger (1989: 24) distinguishes between the 'manifest' and 'latent' functions of organisations:

Manifest functions are the obvious, apparent and usually stated ones. In human services, these appear to have something to do with meeting the needs of the people served, and to allay all sorts of afflictions and miseries... latent functions are those which are hidden, unannounced, underlying, and implicit rather than stated.

Because organisations commonly serve these latent functions first and foremost, functions of which even their members are often unaware, he further warns that the true goals and functions of an organisation cannot be deduced from examining their rhetoric. The disabled people involved in the fieldwork were often very aware of the lack of congruity between organisational rhetoric and reality. All were aware of my involvement with BT, and perhaps because of this knowledge, many expressed opinions about the company and others like it, not all of them complimentary. Many were suspicious of their motivations. Some found fault with the so-called altruism of companies providing equipment and services for disabled people (their manifest functions) whilst others were very concerned about what they saw as the cynical profiteering of telecoms operators and providers (their latent functions). These criticisms will now be considered.

Manifest functions: Altruism or oppression?

It is questionable whether 'altruism' is a motivation that any oppressed person will welcome. Pity is essentially an expression of feelings of superiority (Shakespeare 2000), and disabled people are beginning to recognise that there is a fine line between 'altruism' and 'oppression' (Drake 1996: 158). As Freire (1972: 21) suggests:

In order to have the continued opportunity to express their 'generosity', the oppressors must perpetuate injustice as well. An unjust social order is the

permanent fount of this 'generosity', which is nourished by death, despair, and poverty.

Hence, the disabled people's movement has been critical of the many charitable organisations controlled and run by non-disabled people, supposedly for the good of disabled people, using slogans like 'rights not charity', and 'piss on pity'. The emphasis on voluntary approaches to securing disabled people's access to communication systems, risks turning disabled people into 'objects of pity dependent on the charity of others' (Barnes 1991: 98) - in this case, dependent on the benevolence of corporations. Some of the more politicised people I spoke to were unhappy about such motivations:

Caroline/fg3

I think we've got to be quite careful about where they're coming from ... if they're sorry for us, or want to be seen to be doing good - like they might sponsor a disabled swimmer... rather than doing it from a 'well, you should be able to use our equipment same as everybody else. It's the company's failing not yours'.

BT's 1996 publication *Putting Disability on the Agenda*, does indeed have a lengthy Appendix describing its good deeds under 'The Community Partnership Programme'. Corporate sponsorship of disabled swimmers, paralympians and abseilers seem to be key priorities. Their links with charities are further strengthened by the disability organisations they choose to consult with - exclusively organisations *for* disabled people. Consultations with organisations *of* disabled people must become a priority for such companies. Mobile phone companies, like their terrestrial counterparts, are eager to jump onto the disability bandwagon, by for example funding disabled people's sport. A recent One 2 One advertising campaign featured two disabled footballers, artfully filmed in black and white. The company's sponsorship manager is quoted as saying "One 2 One is totally committed to creating awareness and fundraising opportunities that help make a positive difference to people's lives" (One 2 One 2000: 1). When however I e-mailed them requesting

information about the accessibility of their products and services - things which could make just such a difference - I received the following reply:

Please be advised that although this area is something that One 2 One do not currently support, we can however advise you that One 2 One are actively looking to developing our Customer Services to incorporate people with special needs.

Yet again then, it seems that disabled people are being cynically used to give the illusion of a company that 'cares'. This situation must be remedied.

Latent functions: Disabled people as profit generators

properly managed programmes which address the needs of disabled people can open up new market opportunities. They can be profit generators rather than cost enhancers. (BT 1996: 28)

A number of people were critical of the cynical way in which companies exploit their disabled customers in the pursuit of profits, and were unhappy about being seen as 'profit generators'. Danielle spoke for many when she said:

Danielle

They see disabled people and it's like money. We can make money out of this... And basically businesses are just milking everybody for every penny because they know it's a need and it's a necessity, and people will pay for it.

However as Andrew points out, not everybody is able to pay for expensive communication equipment, however much they might need it:

Andrew

I know they 'ave got to make the money, but if you 'aven't got enough money to get one, how do you get one? To me it's stupid. It's all right for these rich people and that lot, but for such as people who's poor and that - that's 'ard.

Graham suggested that companies should be using their profits in ways which were more beneficial to disabled people, perhaps helping them to finance equipment when necessary.

Graham/fg2

When you get a well known company... making all these profits... surely some of that money that you're paying towards having your phone, surely some of that could go to make available, to buy equipment such as computers to make it easier for people, rather than *using* them... Surely they could put something back. They advertise and things don't they, saying they're making it cheaper for people to talk and all that, but I mean if you haven't got the equipment! You know, it mystifies me sometimes! They're making all this profit! They've made millions and millions of pounds... You know, like you get companies sponsoring things. Why don't the companies use their money more beneficial to people?

A lot of criticisms were made about the price that companies charge for equipment and services - a society-wide problem, but a particular problem for disabled and older people who are already financially disadvantaged (see chapter Five). Several of the older participants were particularly angry about the cost of renting their line, especially since their call charges were relatively low:

Maude

I tell you what I would wish. You know when your bill comes in - well my charge for my line is always a lot more than what my calls are... It's outrageous what you pay for your line I reckon.

Nancy

Rental, line and... VAT. And then it's dearer than all your calls!

Maureen/fg1

You can tell British Telecom that I think their rental line is far too dear! I think it's disgusting what they charge for the rental line for the telephone! ...I don't think

British Telecom do as much as they could. That line rental would be the biggest help to a lot of us disabled people and maybe some that aren't... and then there's the elderly as far as line rental goes. They could cut that down. Because we only use it for more or less emergencies and for keeping in contact with family and friends that are there to help us when we need it.

Like Maureen, many participants were aware that access to communication systems was not simply an issue for disabled people. As Helen points out,

Helen/fg3

But what if you're a non-disabled person who's on a low income who can't afford a computer because of that? You know I'm just trying to - I'm not giving an answer to this. I'm just saying that's the kind of - it's a wider split isn't it?

However, it seems that there are certain ways in which disabled people are further disadvantaged. Whilst many of these additional barriers can only be removed through social manipulation (see Chapter Five), manufacturers could do much to make access less problematic for disabled people. The government is also culpable in its regulatory role. Many companies now pay lip service to access for all, employing fashionable concepts like 'universal design' and 'user involvement', and voicing a commitment to widespread information provision. How much this rhetoric has affected disabled people's reality is debatable however. The three areas of universal design, user involvement and information provision will now be examined.

UNIVERSAL DESIGN: RHETORIC OR REALITY?

Provision for disabled and elderly users of telecommunications equipment and services should be inclusive and based on the concept of 'design for all'. We believe that equipment and services should be available in ways that do not exclude elderly and disabled consumers. This approach relies on the positive actions of telecom companies...It also depends on OFTEL's continued ability to

enforce license obligations and to champion the additional needs of disabled and elderly people in relation to telecommunications. (DIEL 1998: 1)

Many corporations (eg: BT 1996; Microsoft 2000) now express a commitment to universal design: 'The design of products and environments to be useable by all people to the greatest extent possible, without the need for adaptation or specialized design' (Connell *et al.* 1997: 1). Universal design we are told, is better design for everybody, not just for those with impairments (Microsoft 2000; Ransom 1994). Apple computers have led the field in incorporating special features directly into their standard operating system, to benefit users with certain impairments (Vanderheiden undated). Features like 'sticky keys' for users who do not have the use of two hands, 'mouse keys' which enables the mouse to be controlled via the keyboard, and 'close view' which enables the screen to be enlarged, have now also been adopted by Microsoft. These moves are undoubtedly a step forward for many IT users. Jessica for example finds a mouse difficult to use, but is able to use a standard interface at work using a 'mouse keys' feature. However for others, expensive adaptations are still necessary. It seems then that there is substantial room for improvement in this area.

Universal design still seems to be a fairly abstract concept - not so much 'an identifiable style but a way of thinking about the design process' (Adaptive Environments 2000: 1). In America, various advocates of this way of thinking have compiled seven *Principles of Universal Design* (Connell *et al.* 1997) in an attempt to concretise the idea. These principles include consideration of different physical and sensory requirements, as well as attention to unnecessary complexity and stigmatisation. They are intended simply as a guide to designers 'to better integrate features that meet the needs of as many users as possible' (Connell *et al.* 1997: 4). As yet, there is no compulsion to integrate such features however, and any moves by manufacturers are voluntary. As the fieldwork demonstrated, this has so far not been sufficient to secure disabled people's access to mainstream technology. Universal design will perhaps need to be enshrined in legislation before disabled people will be fully included in the design process.

The reality behind the universal design rhetoric will now be considered - by examining the continuing need for specialist add-ons, by looking at the particular

problems encountered by those with multiple impairments, by considering the complexity of much modern technology, and finally by considering the stigmatisation which accompanies the use of 'special' equipment.

Universal design or specialist design?

The key to access is universal design of telecommunications equipment and services rather than costly adaptive equipment that puts the burden on the individual. (Ransom 1994: 172)

Because of many disabled people's continuing exclusion from mainstream technologies, and their reliance on specialist equipment and adaptations, the same system is often more expensive for disabled people than for their non-disabled peers. It can often put technology beyond their reach altogether. This was a major concern amongst the disabled people who talked to me. Max for example has no sight, and his partner is also visually impaired. They often have to resort to expensive specialist equipment. They have for example a talking microwave and talking kitchen and bathroom scales. All such 'special' products involve a cost penalty (Feeney and Galer 1983). Max was aggrieved about the price of a new electronic personal organiser with speech input and output - something he would find extremely useful:

Max

You're talking two hundred for that, two fifty something like that... The ones that you can see - they're about twenty quid aren't they?

Despite the many stated commitments to universal design, Max pointed out that standard products are actually becoming more difficult for people with visual impairments to use:

Max

The old [stuff] you'd 'ave like a dial to turn wouldn't you, or a switch to switch? They're all flat now to the face a lot of them. Unless you've got really good touch... a

lot of blind people 'aven't you know, especially with diabetes and stuff like that, [it's] very, very hard to feel that stuff.

Similar sentiments were expressed about computer software. Helen talked fondly about 'the good old days of DOS', and does not see Windows as a positive move forward, particularly for those with visual impairments. She has been forced to learn Windows for her job, but describes it as a 'bit of a nightmare':

Helen

The keyboard commands aren't there in Windows, and they were in DOS...And it certainly irritates me where people assume that 'cos you're using Windows it's easier... it isn't. Definitely not with speech.

The necessary software to operate IT with speech input and output is of course another extra cost. Max has been put off buying a computer with Internet access by the price of the adaptations he would need.

Rather than calling for universal design principles to be incorporated, to an extent the group was resigned to the fact that adaptations were necessary. They were however critical of the high prices charged for such specialist equipment:

Helen

I understand that the companies that produce like particular technological stuff like speech software all that kind of thing - I understand they're in a small market, but their prices are ridiculous!

Whilst universal design remains an unfulfilled ideal, perhaps the only equitable way forward is through universal pricing structures. This seemed a popular solution amongst participants:

Danielle

I just think it's ridiculous... because I mean like normal people, people that haven't got a disability - they can go in and they can pick packages, you know basic packages... And I think they should do that for disabled people... 'OK you can have these certain packages on yours and it's not gonna be at any extra cost. We'll chuck it in for you', you know... Society should be helping disabled people and not hindering them. You know... expecting them to fork out for a computer that probably would cost a normal, able-bodied person five hundred pound and... probably cost a disabled person after all the adaptations and stuff like that probably a grand, even more than that! Which we 'aven't got!

Caroline/fg3

That's the answer! That all machines have all these things available, with it being put together a package for yourself. Say you can have so much equipment for a certain price and you choose what that sort of equipment is - whether you want a different keyboard to make it more accessible, whatever. That's the price of a keyboard.

However, once again, any such moves by suppliers would be purely voluntary. There is no legal precedent for such actions on the part of manufacturers, and most would resist such moves. BT (1996: 34) for example voice concerns that providing free or low cost services for disabled people might be interpreted as discrimination against non disabled people. They further suggest that many disabled people are against special pricing themselves, as their goal is equality - 'equality of access to the network at an affordable price'. As long as expensive adaptations are needed to make equipment accessible, and the extra costs falls on the individual, there can however be no 'equality of access'. Since manufacturers are resistant to universal pricing, it seems that outside funding may be required to equalise access whilst there is still a need for specialist equipment. At present, such assistance is available only for those in employment or in education. A government who espouses a commitment to equality of access should consider making such funding available to all disabled people irrespective of their status as a worker or a student.

This kind of funding does not come without its problems however. Any crumbs thrown from the State coffers must inevitably be preceded by a disabling assessment procedure, and getting assistance from non-governmental organisations (NGOs) such as charities is similarly demeaning. Furthermore, 'special' equipment can also be stigmatising equipment as will be considered below.

Universal design or stigmatisation

All the respondents had some sort of telephone equipment in their homes. Not all had the most appropriate equipment for them however. Most of the group were using standard telephones. Hands free phones were used by several people who had difficulties holding a receiver, and cordless phones were popular amongst those with mobility impairments. Some had phones with a volume switch so they could hear the caller more easily, or larger buttons for ease of dialling. Others had telephones linked into their Possum control system, enabling them to answer the telephone with a foot pedal. Many, particularly those with speech impairments admitted that they avoided using the phone if at all possible, saving it for emergencies, or to talk to people they knew well.

Whilst awareness of the various products that are now available was fairly low (see below), many people were 'managing' with standard equipment which was not ideal for them. It seemed there was a reluctance to consider 'special' telephones, whilst they could cope with the equipment they had. This seemed particularly marked amongst the older participants. Several respondents were using phones with extra features such as volume switches, but still found it difficult to hear. Frank had heard of devices that might improve this situation, but was adamant that he could 'manage all right'. Others, like April have difficulties holding a hand set. April admitted that she would find a hands-free phone useful, but seemed reluctant to get one: 'No, no. I manage all right... I can manage to pick me phone up and jam it under me chin.'

As Frank Bowe (1988: 35) suggests, there may be some resistance to the use of products which are not used by the general population as they effectively draw attention to the fact that 'special help' is needed. Many people then would rather put

up with inconvenience than use a stigmatising product, and this tendency may be reinforced by others. Susan Lonsdale outlines a study which demonstrated that blind people were pressurised by their friends and family to try and walk without their white canes (Doshen and Doshen 1989, in Lonsdale 1990). (Similarly, I was once urged by a close friend: 'don't let them put you in a wheelchair'). Whilst standard telephones now have many features that can be helpful for disabled people, many would still benefit from using 'special' equipment. It seems possible though that such equipment may have a stigma attached and therefore be avoided.

It is suggested however that even the use of mainstream technologies can be stigmatising:

the dominant discourse on disability attributes negative ascriptions to people who have too close a relationship with technology, in part as a result of valorization of the notion of autonomy from others in Western society (Corker and French 1999: 5).

The fieldwork demonstrated that many disabled people have been influenced by this discourse, and that a fear of losing perceived autonomy has created a certain reluctance to use *any* technological aids until absolutely necessary. There was a widespread acceptance amongst those who saw themselves as having less significant impairments, that technology was something that those with more severe impairments needed, albeit something that they themselves might need to use as they aged. Kate's desire to 'use it or lose it' has made her reluctant to use even relatively basic technology - in this case a car roof box for her wheelchair:

Kate

I'm very determined to try and use what I've got left so as to be as independent as I can be. Just like getting this roof box that I've just got for my car. It's a massive blow to the pride, it really is, and yet I know it's going to give me independence and I'm going to be able to do things. And so I just say, 'well - yeah - bite this bullet'. It's not very nice, but yeah. I think it's like, when you lose something, you only realise how nice it was once you've lost it, and different parts of the body you know stop

functioning, so you think, 'ah - I must appreciate all the others while they're still here'. I feel very determined I'm going to get another manual chair. I feel very determined to use my arms until they won't work, and just appreciate what I've got while I've got it.

Several people expressed similar sentiments, especially in relation to Internet technology:

Frank/fgl

I mean - I should imagine if you wanted a computer, you've got to be on rock bottom haven't you [laughter] - you've got to be really, really physically - bugged haven't you? You know what I mean? ...If you want a computer and all this lot, instead of going to the shops, you've got to be right down on the bottom level haven't you?

Agnes

I'd want to do anything if I know I can get out. But when I know I can't get out then I'll have to use such as that you see... You always see somebody worse than yourself. I think these things are for ones such as them.

Danielle

I like to try and keep myself active while I can be active. I don't want to be thinking well, this is the easy option out. I mean, I agree with it there for people that it is a way for them to do their shopping ... and do stuff like that. But I think for people that still can, [they] should still have the opportunity to go out and do it. So I probably wouldn't use it as yet. But who's to say how my disability will go and what will happen in the future?... I probably would use it... if there was a need to use it.

Others, like Max questioned the thinking that those with severe impairments needed such technology more:

Max

I know physically some people need it - like Curtis and that - it's brilliant for him and he really needs it. But then if the access was good, transport was better, then you wouldn't need it would you?

Whilst as Max suggests, the housebound status of many older and disabled people is created by an unthinking and disablist society, and requires social manipulation for its removal, the fieldwork demonstrated then that many disabled people think differently. They perceive that ICTs are there to help people who 'can't get out', and consequently often seem reluctant to use it themselves. Until this hegemonic discourse is overturned, it seems that the use of ICTs will continue to be seen as stigmatising, and many who might benefit from their use will continue to resist them. Universal design principles will perhaps reduce the stigmatisation attached to specialist add-ons, but may do little to affect this larger problem.

Universal design and multiple impairment

Whilst paying lip service to universal design principles, the new found interest in disabled people as a marketing opportunity has largely focussed on research and development of new products which are physically accessible for those with specific kinds of impairment. *The BT Guide for Disabled People* produced by their Age and Disability Unit is for example divided into four impairment specific sections aimed at those with hearing, speech, sight, or mobility and dexterity impairments (BT 1999). Whilst this range of products has undoubtedly made using the phone possible for many people, many are still excluded. No thought is given to the difficulties faced by those with cognitive impairments or learning difficulties, and there is no consideration of those with multiple impairments.

Of those interviewed, less than half fitted neatly into just one of BT's impairment categories. The majority had multiple impairments and were not therefore being catered for adequately. This was particularly true of the older participants but also affected younger people like Melanie. Melanie has been trying to find a mobile phone

that she can use. She has difficulty holding things, and is unable to use voice activation because of her speech impairment. It seems that at present there is no suitable device for her. Attempts to deal with specific, single 'deficits' by designers are not working. It is time to move on.

Universal design and complexity

The complexity of much modern technology appears to be a major barrier to many people. However, this is frequently interpreted not as a fault of the technology, but of the person using it (Thornton 1993). Edith for example told me: 'I think it's me who's silly who can't take it in'. Factors such as age and gender seem to play a role in how complex technology is perceived to be, and as will be discussed later, sub-standard education, lack of appropriate training and backup support, low self esteem, and lack of experience all conspire to make technology difficult to use (see Chapter Five).

Domestic technology is not simple technology. Women participants were particularly likely to admit to being defeated by it, especially those who were older. Many expressed difficulties in programming numbers into the memory on their telephone. Maureen for example could not manage this at all, and Esther had to get her grandson to do it for her. April confessed that she left use of the video to her husband because she 'wouldn't know where the 'eck to start!' Not surprisingly then, computers were seen as being very complicated and difficult to use. Deirdre (fg4) has never tried to use IT, but told me 'I'm not brainy enough for t' computer!' Maude has tried IT and admitted 'I think it's very complicated. And it gets more complicated each time'. This complexity causes particular difficulties for those who have difficulties remembering things, an impairment effect often experienced by those who have had a brain haemorrhage, or have conditions such as MS. Rita for example has tried a computer, at her resource centre, but does not remember enough to want to do it again. She can only remember how to turn it on. Edith has her own computer supplied through the COL project, has similar problems remembering what to do, and would benefit from a more self-explanatory interface. She has difficulties switching between

the various computer functions, and compared her system unfavourably to the television:

Edith

How d'you get the things on? Like the television, you can have programme one, programme two, or programme three. If you want it on one, you just switch it on one. That one doesn't go anywhere! Can't get anything!

Kate also has a COL computer, but despite her education (an undergraduate degree) confesses:

Kate

I'm not naturally a computery sort of person. I'm not an academic ... I'm sort of arty. I'm much more hands on and creative. Yes - I'm definitely the creative side rather than the thinky side.

Maureen also told me she did not have the right sort of mind to deal with modern technology like photocopying machines: 'To start with - I'm not very good at English... I'm not very academic'. She is obviously worried about the implications that increased reliance on IT might have for people like her:

Maureen/fgl

And what happens to these people... that can't grasp a computer? 'Cos even some of the young ones even, some of them can't grasp the full technology of the computer. No matter how brainy they can be, but it doesn't mean that they can grasp all the computer... just the same as me - they don't want to know.

As Maureen suggests, there is an assumption that younger people will inevitably find IT relatively simple. Many of the older people I talked to boasted about their computer literate grandchildren, but the general opinion seemed to be that lack of exposure to modern technology was more of a problem than chronological age (see

Chapter Five). Some, like Frank insisted that they could learn to use a computer had they the inclination and the appropriate training:

Frank

It wouldn't frighten me - you know if somebody explained to me. I mean, I'm not that bloody thick I wouldn't tek it in.

One of the focus groups was critical of the way that companies mislead consumers about the simplicity of computing:

Ray

It can be very daunting when you first start.

Caroline

And they don't sell them with that do they. They sell them 'oo you're going to take this box home and you'll be able to do it all!' [laughter] The whole family gathered round you know. Your family all there pressing buttons ...

Ray

That's how they advertise it - you just plug it in and it's ready to go!

Caroline

Lies!

Ray

It is though isn't it!

Sharon

Yeah!

(fg3)

The participants in this group were all IT users, and were particularly concerned about the complexity of the Internet:

Caroline/fg3

I think one of the big problems about all this... is that it is not as easy as they make out actually to get on the Internet. You've got to load the software. You've got to work out any glitches that happen. I couldn't do it! I had to get the person that I live with to do it... I can use it if everything's going fine but if anything goes wrong I just don't know what to do. So anybody who doesn't have access to somebody with that sort of information or knowledge!

Helen was put off learning to use the Internet because of its complexity, although since our interview she has actually gone on-line:

Helen

I have friends who use the Internet a lot, and they say there's so much stuff on it, it can be quite confusing, and quite difficult to get off it what you want - just because it's so complex. And I'm thinking, well, if people who use that all the time and are sort of very articulate and very confident people on computers, are saying that - what's it gonna be like for me and for other people who aren't so confident on computers?

Universal design principle three suggests that use of the design should be 'easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level' (Connell *et al.* 1997: 3). This principle appears to have made few inroads into the way that communication systems are designed, despite the rhetoric of design for all. It is imperative that technology, especially computer technology, is made simpler to use, or many millions will become further disadvantaged. Disabled people may be some of the hardest hit, for reasons that will be described further in Chapter Five.

USER INVOLVEMENT

If disabled people are to be 'designed in' to new products from the outset, there is an obvious need for consultation with them and their organisations in order to establish their access requirements. Disabled people 'must not just be seen as recipients of technology, but also as an integral part of the development process' (Shalinsky 1989: 69). Companies such as BT and Microsoft now express a commitment to such consultations, a commitment about which many are unaware. This was evident from the calls for such action from participants. They often felt that companies were not doing enough to ensure accessibility, and should involve their customers more. The lack of progress in accessible telephone design was often raised during the fieldwork. Many were vocal in their criticisms of the products that are currently available, the speed of change, and the lack of user involvement. Take Bill for example:

Bill

I mean special phones like turning up volumes, you've got already, stuff like that. But if you look, they're not moving. They're not moving forward enough... All they're doing is bringing new model phones out... You get these big people, claiming big money - what for? Doing nowt, sat behind [a] desk, having these brainwaves - 'oh we'll change t' shape of t' phone'. They don't really do enough! There's no change in communication there... I just think that firms... should offer the users out there, which is paying these big people's wages, should listen to them people.

Caroline was in agreement:

Caroline/fg3

[They] should be doing things like getting hold of focus groups of disabled people with different impairments, and saying 'right - what is it that stops you using our phone service'.

When I informed her about BT's Age and Disability Liaison Panel, she continued:

Caroline/fg3

You've got to have regular focus groups... which [are] aimed at reducing the barriers to disabled people using the telephone, and show how you're actually dealing with it, you know, proper feedback. I mean you're saying there are such things but nobody knows what actually happens at them or if anything's done about it. You know - a proper report... research done like you've been doing here, but perhaps on a practical - 'right exactly how do people use telephones?' Yeah - if that sort of research is done they haven't got the excuse to say 'oh - it's not possible' or 'nobody wants it'.

The disabled people's movement has made significant advances towards the development of local user-led services (Barnes *et al.* 1999). As yet however, it has not engaged with debates around user involvement in the design of accessible technologies. It should begin this process as a matter of priority. Communication companies seem reluctant to consult with disabled people's organisations, preferring to rely on the input of non-disabled people speaking on our behalf. Whilst 'user involvement' is a step in the right direction, it seems that without more accountability, and more real input from disabled people and their organisations, it may represent little more than tokenism. Since disabled people are seldom in a position where they can design products for their own use, it is imperative that they become more involved with industry, and that their unmet needs become central to research and development programmes. Then perhaps 'universal design' will become not just rhetoric, but reality.

INFORMATION PROVISION

Access to information is fundamental to meaningful participation in contemporary society. Yet disabled people have traditionally been denied adequate information relevant to their circumstances, whether accessible schools, employment opportunities, or social benefits. (Barnes *et al.* 1999: 145-6)

Unsurprisingly, we can add communication systems to this list. Whilst ICTs potentially offer new ways for disabled people to access the information they need (see Chapter 7), it seems ironic that information about these systems is so poorly disseminated (Bjørneby *et al.* 1991). The benefits of personal computers will remain unavailable to disabled people unless new ways can be found to assist them in 'finding out what is new in the area of information technology' (Schworles 1983: 322).

One of OFTEL's functions is apparently to collate and publish information where users would find it of use (HMSO 1984), and corporations also claim to recognise the importance of effective information provision. Microsoft's *Accessibility Policy and Strategy* for example, expresses their commitment to 'empower customers with information to make informed choices about what to use, and make the best use of the products they have' (2000: 5). The fieldwork however, demonstrated that lack of adequate information still represents one of the biggest barriers to disabled people's beneficial use of communication systems. This was true of both telephones, and computer systems.

BT has made important advances in the way it disseminates billing information to disabled customers. Max highlighted how despite teething problems, things have improved significantly for people with visual impairments:

Max

I think BT do a really good job to be honest. I mean, we can get our bills in Braille. We can get 'em on tape if we wanna. We can get told what the bill is, you know before you actually get the bill. The fact that you get about 27 Braille copies and one print one - you know, that's beside the point! No they're getting better - we only got 3 Braille ones last time and 2 print ones. They couldn't understand [at first]. They sent the Braille bill all right... And I said 'well how do we pay the Braille bill at the Post Office?... The people in the Post Office can't read the Braille bill can they?'... After about the fourth or fifth bill they actually sorted it out, we got both of them. So that's good. Course they've got the directory enquiry service for the blind, or for all disabled which is good. And I think they're excellent.

Lesley (fg1) was less impressed however, complaining that 'BT don't do nowt for the blind'. She is not a Braille reader, and was unaware of other ways that she could access billing information. Information about accessible information provision is not then reaching all those who need it. As a National Information Forum report (2001: 19) suggests: 'everyone needs information about information... If services and publications are to help people, they must first know that they exist'.

Many of the participants were making do with inadequate telephone equipment, in part due to poor information provision. Curtis for example dislikes using the telephone because people tend not to understand his way of speaking. He has recently started using e-mail, but prior to this, had never received any information about text-telephony. He was critical of the way manufacturers disseminate information: 'You can't find out anything. Only if you go and ask them. But if you don't know, how can you ask them?' John has no speech at all and communicates with a Lightwriter. He has a telephone linked into his Possum control system, which he can use to call his parents in an emergency, communicating by knocking on a table. He too had never heard of text telephony. (This lack of knowledge would probably no longer be found, since text-messaging has now gone 'mainstream').

BT's main source of information for disabled people is its publication *The BT Guide for Disabled People* (BT 1999). However, very few of the participants were aware of the booklet. I visited the local BT shop on more than one occasion, to try and get additional copies to give to research participants, and was told every time that although they usually had them in stock, they had just run out. The guide can be ordered by phoning a free BT number, but this is a long process which involves negotiating one's way through a series of automated options - a development which many participants criticised. Frank for example needed to ring and report a fault recently:

Frank

I looked in t' telephone book and I found the number for t' phones. 'If your phone's got a star on you can press this number...', and oh, you know, about four or five different

things. And then t' lass come on again, like a talking phone thing about doing t' same, so I put the bloody phone down... You know, you just go 'ah, forget about it.'

It seems then that many people might avoid ringing BT for information, or, like Frank, simply hang up. Even those who are successful in obtaining the BT guide, may not find the information inappropriate. As Maureen told me: 'we can't understand half of what's in the brochures'. A more effective way must be found for providing information to customers, especially to those whose accessibility needs are not automatically satisfied.

There was some agreement that manufacturers should be doing more to provide information, although as the following extracts demonstrate, different ideas as to how this should be done:

Neil/fg2

There's not enough advertisements for what's going on, what's on the market to buy, what kind of telephones... You don't know what's available for t' disabled... I think it should be the company themselves telling people about it any way they can - television or ads in papers.

Helen/fg3

They've got enough money. They could put regular bulletins in, just for one example, the publications for disabled people's organisations. That'd reach a certain amount of disabled people. It wouldn't reach everybody, but if they do that and they sort of put it in newspapers - you know - pass their information [on]. If they disseminated it as widely as a disabled people's organisation would disseminate their information, then hopefully it would get to all the people that needed it.

Andrew thought that social services should also take some responsibility in their capacity as providers of telephone equipment. As will be discussed below, others were concerned that manufacturers of particular products would not give impartial information, and proposed that more innovative solutions should be found.

The problem of accessing relevant information becomes yet more pronounced when information technology is considered. As Max told me:

Max

A basic word processor with a scanner would be enough for us. With speech obviously. But where would you go to get that information? I really don't know. Even RNIB and people like that, they don't seem to know what they're talking about really.

As described previously, the fieldwork participants were probably more aware than most disabled people of developments in communication systems. Some used IT in their work, others were involved in the COL project, and the remainder knew people who were involved. There was a COL computer with Internet access in each of the local resource centres, along with other stand-alone machines. Dot often used the Internet at Colliers, and told me: 'I mean, it's only coming to places like this that [you] get to know about it all. I mean I did not know first thing about computers until I came here'. Despite this, there was a low level of awareness about adaptations to make IT accessible.

Although universal design remains merely a long term goal, physical access to communication systems is improving in certain respects. There are for example a number of products now available which mean that disabled people can use computers more easily, including various input devices, output devices, switching systems, and programs and screens to reduce the risk of seizures. Some participants who had relatively severe impairments were thus able to operate IT. Curtis for example uses a 'track ball instead of a mouse. It's better for me. I can do it with my chin'. He manages to operate his standard keyboard using his nose. Screen readers were invaluable to participants like Helen and Max who have visual impairments. However, information about all such features seems to be very poorly disseminated, so that few disabled people even realise that they would be able to use a computer:

Esther

Not being cruel, but if you had fingers like Sylvia's, you couldn't use a computer.

Frank

No.

Maureen

Computer's no good to me. They keep saying it is. I've got a finger and a thumb that I can use, but I can only use that finger for so long before it starts swelling up.

(fg1)

Similarly, people like Pauline (fg4) and April told me they were unable to use IT because of their epilepsy, despite the fact that screens and software are now available to eliminate the triggers which cause seizures. April enjoyed using IT at work before she acquired her impairments, but now claims it would be impossible: 'It's because of my epilepsy. And also I'd have to be relying on one hand'. Others, like Peter are using computers regardless, despite the fact that his first use of IT triggered a seizure. Knowledge of appropriate adaptations was very low in this area. Dot was one of the few participants with epilepsy who knew that assistive devices existed:

Dot

Somebody told me 'don't stay in front o' t' television, don't use a computer because you'll have a fit if you do'. And I were a bit iffy at first about using computers... I tried one of those special screens though. Yeah - I've been all right with it.

Participants in fg2 discussed information provision at length. They saw a need for impartial information about IT which was not biased by the vested interests of manufacturers or the lack of knowledge of shop staff:

Helen

One big thing that I don't think's been stated enough is that you need information about information technology and communications systems. There isn't somewhere you can go to get at least sign-postings to the appropriate place. Like if you were

thinking of purchasing a computer and you want to know what elements are available to assist you to use that computer - where do you start?

Caroline

Say you go to the shop, even if it's a shop selling lots of different brands, he's gonna want to sell one. He or she is going to get the best deal... well there would be a tendency to do that wouldn't there rather than necessarily find the best package for you?

Helen

And they aren't gonna know about blooming speech software or whatever, if it's not openly commercially available.

(fg3)

They also had ideas for solutions to the problem:

Helen

I'm always in favour of things like at least a basic information guide or directory or whatever that can be sort of put in libraries, disabled people's organisations etcetera, so that you could at least have a starting point. So - it saying 'these are all the different type of things that are available, there's more coming out all the time, but possible places to check are this, this, this, this and this'. That wouldn't take much to put together.

Caroline

What about something like a local authority one stop shop?

Helen

Yes.

Caroline

There's nothing wrong with us getting private funding for that from IBM or whoever else, as long as the advice given at that place was independent, they weren't selling anything, they were just telling you what was available. And it would be in the interests then of the computer firms to sponsor it, and to improve their products because they'd know they were getting talked about. So it could be done with outside

funding. I mean that's Blairism all over i'n't it - the government doing something and getting someone else to pay for it. That would completely tie in with the way they want to go at the moment. So how could they argue against it?

(fg3)

Danielle made a similar suggestion:

Danielle

I mean, there is information around, but for disabled people to actually go into a shop or whatever, it's a big step. And if sales assistants don't know how to handle a disabled person, if they can't communicate with that disabled person, then you know, if that breaks down getting the right thing for a disabled person to actually use a computer instead of being fobbed off with a computer that is wrong. Or you'd find that you've gotta pay like double again to actually get it right because the sales person didn't get it right in the first place. And because you've already bought it and had it for thirty days before you actually realised it were wrong it's tough. So I think there should be a special company that just focuses on disabled people - *computers for their needs*, that has the special training to take time out. And you know you've got the option to come to your home you know or go to a special showroom or something. You know - if you can't get out we'll come to you. And go through it with them and sit down you know, and take time - I think that's what's needed. And it's possible to do you know. It's creating new jobs, it's putting the sales of computers up which is bringing the price down, and it's getting that bit of society that is missing out, that can be a big boon - if they do it right. If they look at it right and do certain schemes right.

Whilst current attempts by businesses to disseminate information to those who need it are felt to be inadequate, it seems that more innovative solutions must be adopted. It is evidently not enough simply to produce brochures, then wait for people to request them. More proactive information dissemination has to be a priority for companies. As well as giving disabled people more rights as citizens (see Chapter Seven), it would make good business sense, as interest in new technology increases

with increasing information (Bjørneby *et al.* 1991). However, whilst companies have a vested interest in selling their products and services, and a financial commitment to their shareholders, such information cannot be impartial. It is important then to distinguish between information provision and marketing - providing information in order to make more profits. The privatisation of telecommunications means that any information businesses do provide is inevitably bound up with profit making. Whilst companies can certainly improve the way they *market* goods to disabled people (Martin 1991), unbiased information which is not contaminated by vested interests would be better provided elsewhere. As long as disabled people are reliant on specialist aids and adaptations to access communication systems, a truly independent body is needed in order to give them the information and advice they require. If such an organisation is to focus specifically on disabled people, as several interview participants suggested it should, preferably it would be controlled and run by disabled people. The lack of such a body is yet another barrier to disabled people's access to communication systems.

SUMMARY

The various companies involved in developing and delivering communication products and services have a long way to go in securing disabled people's access to their goods. Their newly stated commitments to universal design and user involvement are laudable, but any effects are as yet minimal. Any efforts to market their products or disseminate information are woefully inadequate. Market forces cannot be expected to equalise communications access, and whilst any progress remains purely voluntary on the part of industry, disabled people have no rights to accessible communication systems. Policy changes will be required in order to secure these rights. These changes must be prioritised as a matter of urgency or disabled people risk further exclusion.

Such measures will not however mean that disabled people achieve emancipation. Neither will they mean that access to communication systems is no longer an issue.

Disabled people face a myriad of other barriers to their full participation in society - barriers which conspire to make equal access to technology all the more improbable. These must be removed if disabled people are to be included in twenty-first century society. We need access to all areas of life, and an end to institutionalised discrimination and oppression. The next chapter will consider these issues further.

CHAPTER FIVE: ACCESS AND THE SOCIAL MODEL OF DISABILITY

This chapter will discuss the social, economic and environmental barriers which disabled people face in their day-to-day lives. These 'pre-existing barriers' show little sign of dissipating as we launch into the new millennium, and as previously demonstrated, with the ascendancy of ICTs, a new set of barriers now have to be negotiated. The geographical dispersal of families and friends made communication systems an essential tool for anyone who wishes to keep in contact with those who are spatially distant. They are often conceptualised then as breaking down the spatial barriers which increasingly impinge on us all. Disabled people are particularly affected by these barriers, and hence telecommunications are often thought especially important for them. Drawing on the fieldwork, the reasons for, and implications of this increased dependence on communication systems will be examined.

Since disabled people face barriers in so many areas of their lives, it is no surprise that they face barriers to accessing communication technology. Access to this technology is not however always their greatest concern. Many other priorities were expressed during the course of the fieldwork, priorities which will be discussed below. This prioritisation of access needs has made certain disabled people wary about the implications of such technology. Will the virtual 'mobility' that ICTs provide be substituted by policy makers for real mobility and access?

Finally, the main social barriers which prevent disabled people from accessing appropriate communication systems will be considered. As the fieldwork demonstrated, there are complex interactions between various barriers, which make accessing beneficial communication systems difficult or impossible for all but a fortunate few.

'LET THE WORLD COME TO YOU': COMMUNICATION SYSTEMS AND
'HOUSEBOUND' PEOPLE

Communication systems have always enabled contact between individuals who are geographically distant, diminishing the significance of spatial barriers. Telephone communication has been shown to have particular benefits for those who are geographically (Fischer 1992), or socially isolated (Harbert 1997a; 1997b). It is also thought to have a 'potentially liberating' effect for people who are 'housebound' - those who face difficulties in leaving their homes or travelling - 'who might thus be able to carry out a range of activities previously only available after travel' (Short *et al.* 1976: 16). Hence Kate talked about the telephone as giving her the mobility she would otherwise lack:

Kate

I would say the greatest benefit of the telephone for me is giving me mobility. I know that sounds a bit funny but you know, I can't pop round and see somebody for a social... but I can ring them to see how they are. With the shopping, I can't shop round to find different things, but I can find out. Yeah - it gives me mobility really.

In the twenty first century, communication systems offer far more than mere social contact. The ability of ICTs to transcend time and place has intensified (Castells 1996; Meyrowitz 1985) so that a myriad of experiences can now be delivered to us without the necessity to travel (Carey 1999). Some of the participants were enthusiastic about their experience of transcending space. Take Martyn for example:

Martyn

I'm not allowed to go out on me own. I'm not allowed to go down the street on me own. But when I'm on a computer I can do whatever I want on me own. I can go anywhere I want on me own. And as I say, if I didn't have a computer I might as well just give up.

Neil too referred to the Internet as 'another way of getting out'. He added though that he would 'rather have transport and no computer than a computer and no transport' - a theme which will be returned to presently.

As outlined in Chapter One, we can distinguish between two modes of creating contact between humans and their world - one which brings individuals to the experience, and one which takes the experience to the individual. This theme is becoming a common one. Vodafone UK for example, has recently launched its biggest ever advertising campaign in an attempt to reposition the brand. The advertising centres on the slogan 'You are now truly mobile. Let the world come to you.' (Vodafone 2000). Most people then, now have a choice in how they experience the world - they can for example elect to visit a friend, or choose to talk to the same friend over the telephone. Disabled people are not afforded the same choices. Inaccessible housing, transport systems and public spaces all contribute to their reliance on communication systems as a vital means of making contact with the world. Hence many people agreed that telephones were more important for disabled people than for those with more freedom of choice - 'If you can't get out at least you can keep in touch' (Lesley/fg1). Others like Frank, highlighted older people's increased reliance on the telephone:

Frank

I mean when you're elderly you can't get about can you? You rely on t' phone a lot. A lot of people can't get out can they?

Participants in fg3 agreed that the telephone was more important for disabled people, but were emphatic that this should not be the case:

Helen

I'd say it is, but it shouldn't be. Because [of] a combination of transport and environment, it's often more difficult to actually meet up with people in person. And if it's having a two hour telephone conversation in exchange for sitting in a cafe

somewhere chatting, then maybe it is more important for disabled people. But it shouldn't be.

Caroline

And of course that increases your costs and your barriers - if you sit on the phone for two hours rather than nipping round the corner to the cafe for the price of a coffee - as well as not getting quite the same thing as one-to-one contact with people.

(fg3)

The disabled people's movement has traditionally battled for the same choices and rights as non-disabled people to go to the same places, travel on the same buses and live in the same houses. The legislative response has been slow to follow, although the Disability Discrimination Act (DDA) goes some way towards making direct discrimination unlawful (HMSO 2000). Rather than adjusting the outside world as the disabled people's movement suggests, there is more enthusiasm for the alternative option - if disabled people are unable to travel freely, why not take services to people in their own homes? Those delivering services to so-called 'housebound' individuals often adopt an individualised, medical way of thinking, where the focus is on the shortcomings of the individual, not on the shortcomings of an exclusionary society. Conversely, disabled people have insisted that being 'housebound' is not an inevitable part of their condition. They simply have little option but to stay put because 'transport systems were only designed with able-bodied people in mind' (Hasler 1993a: 280). As well as disadvantaging a major proportion of society, this exclusion is also placing an enormous financial burden on that society. Brian Heiser (1995) outlines a report which estimates that the extra costs incurred through bringing services to people denied access to public transport is as high as one billion pounds per annum. As will be discussed in Chapter Six, this 'drain' on the public purse could undoubtedly be reduced through the provision of services via communication systems. The exclusion that disabled people experience would not necessarily be affected however.

'WHAT LIFE D'YOU HAVE IF YOU DON'T GO OUT?'

Technology has made it possible to circumvent the traditional barriers which keep people in their homes, whilst leaving those barriers intact. Whilst many welcome these developments, others are more wary. How liberating can it be to be left unable to travel or leave one's private space - to be effectively segregated within one's own home? Disabled people already face difficulties in going where non-disabled people go, and are not enthusiastic about developments which would keep them at home yet more:

Andrew

To me you've got to get out - out into t' society so you're mixing with people and that. But I think if you're stuck in and you're looking at four walls all t' time you're gonna end up going crazy.

Joyce/fg4

What life d'you have if you don't go out? ... you might as well not be 'ere hadn't you? You might as well be pushing bloody daisies up!

Whilst going out was seen as a necessity, several of the participants admitted that they would like the opportunity to go out more often. Although the disabled people who participated in the fieldwork were less isolated than many - most were regularly attending segregated resource centres and some were in employment - their social participation outside these settings was often minimal. The reasons for this will now be considered.

LOOKING AT FOUR WALLS: BARRIERS TO LEAVING THE HOUSE

A key issue for the emergent disabled people's movement in the UK was the position of disabled residents in institutions. Hence the UPIAS Policy Statement asserts that disabled people 'will never be fully accepted within society whilst segregated institutions continue to exist' (UPIAS 1981: 4). Since the 1950s there has been a gradual move away from institutional 'care' in favour of community based services. Whilst disabled people have largely seen this as an important step forwards (Morris 1991; 1993a), problems still abound (see Chapter Six). There are still numerous ways in which disabled people are kept out of their communities, and away from the 'mainstream of life' (UPIAS 1976: 1).

The very phrase 'community care' is said to have exclusionary implications (Oliver and Barnes 1998). Disabled people do not want 'care', since the concept seems to provide 'a tool through which others are able to dominate and manage our lives' (Wood 1991: 199). As Jenny Morris (1993a: 23) suggests, if personal assistance is defined as 'care', then the 'carer' becomes 'the person in control'. Instead of 'community care' then, the disabled people's movement has called for independent or integrated living. This encompasses more than a mere shift from institution to community. Whilst policy initiatives have been 'preoccupied with care, medicalisation and segregation', the disabled people's movement has concerned itself with 'participation, integration and equality' (Priestley 1999: 77). However, many barriers are in place which hinder disabled people in their efforts to live 'independently':

Independent living for disabled people necessitates a physical environment which does not disable them, But because they have traditionally been excluded from the mainstream economic and social life of the community, a physical environment has been created which does precisely that. As a result, ordinary or mainstream housing, transport systems and public amenities and buildings are often out of bounds to disabled people. (Barnes 1991: 149)

So, despite the move away from institutionalisation, inadequate housing and transport, and an exclusionary built environment, still serve to keep disabled people

segregated - albeit within their own homes (Barnes 1991; Imrie 1996; Imrie and Kumar 1998).

Whilst communication systems can provide an invaluable means of contact with the outside world for disabled people who are placed in such a position, they are still limited in their choice of how they make contact with the world. As Martyn told me,

Martyn

I live in a village. I can't get in shops, but I can get in a supermarket. I find it difficult to get in the library without help. On a computer I can pick any library I want, I can draw a book out on the computer, download a book, print it out, read it - on a computer. And I don't have a time limit to return it... And there's literally thousands of books I can choose from... I'd want to... be able to go out to the library. But... they seem to put obstacles in the way - like steps... I can't even go for a haircut on my own because there's a step. I have to have somebody with me, and it has to be two people lift me up to get into the barbers.

Mobility has been described as 'a fundamental feature of human life and society...one of the important factors in our ability to participate in society' (Napolitano 1996: 30). Zygmunt Bauman (1998a), whose writing on consumer society will be considered in Chapter Seven, further suggests that in today's society, the 'dimension along which those "high-up" and "low-down" are plotted... is their *degree of mobility* - their freedom to choose where to be'. Disabled people are currently being denied this freedom. Hence Sue Napolitano (1996: 30) wrote from her own experience of living with mobility impairment, and bemoaned the fact that 'when somebody has this kind of impairment, it is perceived by fellow non-disabled citizens as somehow "natural" that lack of mobility should follow'.

Whilst communication systems can enable contact with a world that can be inaccessible and even hostile if encountered directly, this 'virtual' contact is not necessarily the same as the direct contact which disabled people are currently denied. Many disabled people wish to participate directly in society, and prioritise changes which would give them this opportunity. Some are concerned that technological

solutions to the problem of being 'housebound' might be used by policy makers to substitute for more meaningful changes. These areas will now be considered. The discussion will focus primarily on computer-based ICTs.

GET YOUR PRIORITIES RIGHT!

Andrew

I think they should, before computers come out, they should - like such as seeing to roads and seeing to making shops accessible. They should be concentrating on that first. Like say somebody's in a wheelchair... that's giving them a bit more independence then.

Frank/fg1

If Patrick had this computer at home that he could ring in and say get a taxi, when the taxi come it would be no good to him - can't get in one. You know what I mean? I mean, there's a lot of things what's wrong that should be priority before all this stuff comes in.

It is noted that poorer countries 'often make fresh water a far greater priority than access to cyberspace' (Jordan 1999: 90). Likewise, access to IT was simply not a priority for many research participants. Instead they prioritised better housing and access to public buildings, improved healthcare and service provision, widespread changes in attitudes, accessible transport systems and so on. Whilst in agreement that access to communication systems is not a top priority for disabled people, some did highlight the increasing importance of such access:

Caroline/fg3

Just to do the things in modern life which are expected of a person, a computer or access to some sort of word processing stuff, I would say is very important... An

awful lot of things are now only going to be available through that kind of equipment... And I'm not saying that a computer is as important as an accessible toilet [laughter]. That's a basic! Clearly all this is priorities. But I think it is becoming almost essential in modern life.

It seems then that disabled people's inclusion in the twenty first century will only be secured through a combination of strategies. Access to technology is vital. So too is access to the wider world. The fieldwork demonstrated a widespread apprehension that technological access will be prioritised by policy makers above other more basic forms of access in areas such as transport, housing and the built environment, thus compounding the difficulties that disabled people already face in getting out into the world. These concerns will now be considered.

THE TECHNICAL FIX REVISITED

Bill

But what's it taking over? It's taking over access - 'oh we'll get a computer for a disabled person and we don't 'ave to improve access, so we'll save money on access.'

As discussed in Chapter Two, there is a tendency in today's society to substitute technologies for real solutions to social problems like disability. Furthermore, with the increasing power of tools, you get a 'barring of alternatives' (Illich 1973: 23). Hence, as Caroline (fg3) highlighted: 'it's getting so that you cannot get access to a great many things unless you have access to a computer'. One commentator asks:

To what extent is technology substituted for the changes necessary to enable a citizen to integrate into the social and economic structures?; To what extent are efficient and cost-effective technologies developed and deployed at the expense of rights? (Rioux 1997: 110)

These questions were a major concern for some research participants.

Bill's discomfort with the COL Project for example, was underpinned by fears that IT was being used as a technical fix, thus diverting attention away from the real, social causes of disablement. He anticipated that ICTs could be used to keep disabled people segregated yet further in their homes: 'I honestly do think it's like, put disabled people to one side. It sort of like keeps 'em in. And if that's the case I don't want no part of it.' Whilst very aware of the potential benefits that communication systems could afford, he was ultimately cautious about the significance that those in power might attach to these benefits:

Bill

It's this new technology thing like City-on-Line, computers - it's gonna take over the access. It's like are they gonna start issuing every disabled person one like they do mobility for a car, then more or less say 'right - you can do your shopping from 'ome so you don't 'ave to come out, and we don't 'ave to make [town] accessible, so you've got no need to come out of your 'ouse?... That's my big worry about it, my big feeling about it. They could. And a lot of people who are more powerful than the councillors that are doing this scheme could make that 'appen... It's like chain you to a kitchen sink sort of thing, you know what I mean? It's sort of like chain you in front of a computer.

Caroline raised the same issue:

Caroline/fg3

That's the [thing] with the whole of the latest communications stuff isn't it? It can leave us more isolated than we were before... it's the perfect excuse not to change general access, not to do anything about it. Yes, it's a double-edged sword and we've always got to be aware of that.

Helen was similarly concerned about the assumption that:

Helen

... if somebody has access to something through technology i.e. down a modem, then they don't need to make other things accessible, you know... shopping that kind of thing... that's something that you need to watch.

Such moves would be devastating, especially for those without access to the relevant technology. As one commentator points out: 'if these services become replacements for local shops and banks and yet are inaccessible then disabled people will be even worse off' (Carey 1999: 11).

The fieldwork demonstrated that there are many barriers in place which limit disabled people's ability to use technology in a beneficial way. Those barriers which serve to make people 'housebound' are significant in this respect. However, the fieldwork demonstrated that the most crucial barriers which prevent disabled people from accessing communication systems are financial, educational, or rooted in the various 'psycho-emotional' aspects of disablement. These areas will now be considered.

MONEY'S TOO TIGHT TO MENTION: ECONOMIC BARRIERS

Martyn

I would say, no matter which way you look at it, the computers are in, they're going to get better, they're going to help disabled people a lot more. The only problem's going to be finance - who is going to pay for it. And nobody wants to. They all want to: 'oh yes sir, we're gonna do this for disabled people'. As the novelty wears off, they don't wanna know.

Danielle

I'm not rich enough yet! [laughter] I want one one day. I want to have me own, but you know... they're so expensive. You know, they are an arm and a leg. And then

you've got to keep up with it because technology - I mean they always say if you were to buy your computer you can always guarantee the next day it's out of date. So it's just costly updating it with technology and stuff like that you know.

A recent survey carried out by the IT-for-All initiative - 'a partnership between Government and business, to promote the wider uptake and availability of technology in everyday life' - includes a subheading *Removing the Barriers to IT* (DTI 1999: 9). Of the 32% of respondents who thought there was a barrier present, 41% identified cost as the main barrier. The survey also demonstrated that the main users of the Internet are still male, between the ages of 15 and 24, and in the higher socio-economic groups.

It comes as no surprise then, that of all the barriers standing between disabled people and their beneficial use of communication systems, economic barriers loom largest. For many of the participants in the fieldwork, purchasing a computer with Internet access was simply not an option. More than half of the disabled people living in this country are living on, or below the poverty line (Berthoud *et al.* 1993). Most are excluded from work and reliant on benefits (Berthoud 1995). As UPIAS (1976: 14) argued disabled people's poverty 'is caused by our exclusion from the ability to earn an income on a par with our able-bodied peers, due to the way employment is organised'. Older people are similarly excluded from the productive process (Phillipson 1982), and often survive on meagre pension incomes. Hence over half of pensioners are also living 'in or on the margins of poverty' (McGlone 1992: 5). The type and duration of work performed pre-retirement determines resources in later life. Hence older women, and older people from other oppressed groups are particularly financially disadvantaged (Arber and Ginn 1991; Estes *et al.* 1984).

The economic difficulties faced by disabled people will be considered by examining access to employment and the benefits systems, and the additional costs which are associated with impairment. Finally, the need for free or low cost provision of communication systems will be briefly explored.

*Giz a job! Access to employment**Max*

I mean, let's face it, most blind people aren't working! So where do you get the dosh to pay for it! I mean as it happens we're lucky! I'm working, and we're fairly well off I suppose, and we could probably afford it! Well certainly in the next few months we should be able to afford it.

Max was one of only three interview participants who were in employment. Six had never been in paid employment (of these one was bringing up children). Andrew and Hugh were among them. Stanmore Hill Resource Centre was once a sheltered workshop, where Andrew used to do what he described as 'slave labour'. Hugh had been similarly exploited. He once worked long hours on the cloakroom in a nightclub, and never received any payment for his efforts. Nine of the remaining participants had had no paid employment since they acquired their impairments. Patrick for example worked on the railways for twenty four years: 'I had this accident, they didn't want to know me!' Two women had left their jobs to look after children, and one to look after her disabled brother. Frank retired at sixty-five, but continued to work part-time until his wife became ill and needed support at home.

Whilst this was not intended as a representative sample of disabled people, the picture in the wider population is similarly bleak, with 78% of disabled people reliant on benefits as their main source of income (Martin and White 1988). Many of those interviewed told me they would welcome the opportunity to enter or re-enter employment, although some were concerned about losing the benefits which they had often fought hard to secure. Others like Dot were quite happy to be classed unfit for work: 'I don't mind being disabled. I don't mind not having to go to work'.

This attitude is becoming increasingly unacceptable in a society governed by the politics of the third way, and emphasising the primacy of individual responsibility - particularly that of finding employment (Blair 1995). New Labour guru Amitai Etzioni (1995: 144) advances a communitarian position on social justice which stresses that:

People have a moral responsibility to help themselves as best they can. At first it may seem heartless to ask, say, disabled people, older people who have lost their jobs, and minority young people who have suffered discrimination to participate actively in improving their lot. There is a valid sense that we owe them, that they are entitled to our help. But the laying of a claim to participate actively in advancing their lives on those who are disadvantaged in one form or another - rather than to lie back and wait to be compensated, lifted, and preferred - is based, first of all, on a concept of human dignity... people should not be exempt from responsibility for themselves - for their own good.

What better way to take responsibility for oneself than through actively seeking work, or striving to make oneself more employable? As one critic argues, poor people are now being presented with 'a slogan in place of assistance: "Find a job"' (Edelman 1999: 4).

According to Blair (1995: 14), 'opportunity and responsibility go together'. Hence New Labour does not aim to keep people on benefits, but to 'grant the financial independence that comes from employment'. The government is currently attempting to 'encourage' disabled people to shoulder their responsibilities with its New Deal for Disabled People (DfEE 2001). Training in information technology is a key component of this initiative. Far from representing anything 'new', it is the latest in a long line of policies focussing on labour supply rather than on demand-side considerations (Barnes *et al.* 1999; Hyde 2000). The emphasis then is on making individual disabled people more employable, rather than changing workplace environments and practises (Hyde 2000; Roulstone 2000).

The continuing 'absence of policies aimed at the creation of a barrier-free work environment' will continue to hamper most disabled people's efforts to enter or re-enter employment (Barnes *et al.* 1999: 116). Benefits then will remain essential to the financial survival of the majority of disabled people. However, with the continuing erosion of state welfare and the increased focus on responsibilities above rights, even the safety net provided by the benefit system may be withdrawn. From being classed as the 'deserving poor', disabled people, along with those from other marginalised groups, are now being described as 'socially excluded' - a group given no attribution of deservingness (Jolly 2000; Sapey 2000). As Sapey (2000: 633) suggests:

[S]ince 1997, the Labour government in the UK appear to have been challenging the hegemony of care through a range of proposals for the reduction or re-targeting of social security benefits for disabled people... However this attack on the systems of support has not been accompanied by a similar pressure on the social barriers to employment and, as a result, a process of social exclusion from the informational economy is likely to arise, which may cause a harsher form of disablement than was associated with the hegemony of care.

The 'hegemony of care' is not without its critics however, with the disability benefits system being described as 'a key component in the discriminatory process' (Barnes 1992b: 3). It is nonetheless essential to the survival of many disabled people. The current state of this system will now be briefly considered:

Access to benefits

Kate

What I feel is really sad for a disabled person and also a lot of other people - when you have to ask, you have to beg for benefits and you have to declare your soul to the world... But that's really demoralising... They come and they ask you so many personal questions and you feel because they're asking you, and because they're going to give you something you have to tell them everything.

Since the advent of the Welfare State, the vast majority of disabled people have been dependent on 'State Charity' (UPIAS 1976: 15) in the form of welfare benefits. As Kate describes above, eligibility for these benefits is based on demeaning professional assessments of need. The benefits system not only provides disabled people with an inadequate income, it also 'compounds their dependence upon professionals and professional organisations and, most important, does not facilitate their integration into mainstream employment' (Barnes 1991: 98). It certainly does not provide people with sufficient means to purchase commodities such as computers and mobile phones.

Barnes (1992b: 5) writes about 'the myth that disabled people are well catered for by the welfare state and... are financially better off than other sections of the poor'. This myth it seems, is alive and well. A worker at Colliers Resource Centre told me that many users of the centre were 'rolling in it', and receiving substantial amounts of

money in benefits. Danielle was one resource centre user who was anxious to dispel this myth:

Danielle

You know society thinks that we get all these benefits and all this money and we don't! You know we've still got to live, still got to pay our bills and stuff like that.

In a similar vein, Jay Ginn (1993: 43) challenges 'the myth of elderly affluence' which is increasingly perpetuated by politicians, academics and the media (Binstock 1984), arguing that it may help to legitimate moves away from state pension provision.

Whilst conducting the fieldwork in March 1998, I met up with a group of disabled people from Colliers Resource Centre at a Disability Action Network (DAN) demonstration against the introduction of the Benefits Integrity Project - an initiative set up to check the validity of existing Disability Living Allowance (DLA) claims, 'and where appropriate, to disqualify entitlement' (Department of Social Security 1998, in Hyde 2000: 330). The anxiety that the project caused was understandably high, with many concerned that their benefits would be cut. As Melanie asked:

Melanie/fg3

But if you are disabled and you can only access a computer at a centre or at a college because you can't afford to buy one because of benefit cuts. Where are you then?

Melanie summed up the concern of many benefit claimants about the increasing dependence on expensive communication systems:

Melanie/fg3

I feel because I'm on a low income and I live with my parents and they keep all the benefits, I've got no chance of buying a computer of my own... And its scary to think that people are going to become dependent, because there's people like me who can't afford to buy one.

Maureen was particularly concerned about the additional expenditure that many unwaged parents now feel they have to make: 'they're getting themselves into debt by trying to buy their children the computers'. Whilst this compulsory consumption is a problem for all those who lack resources, there are ways in which disabled people are further disadvantaged, as will be considered below:

Living beyond one's means: The additional costs of impairment

Disabled people and those drawing pensions are not the only groups who are economically disadvantaged in Britain today. A recent report by the Organisation of Economic Co-operation and Development demonstrated that Britain has the worst record for poverty in the so-called 'developed' world (Denny 2000). However, the poverty that disabled people experience is compounded by the additional costs which are associated with impairment. A disabled person with a similar income level to a non-disabled person will end up poorer, because their basic living costs are higher (Barnes 1992b). For many disabled people, these additional costs increase yet further as they age (Zarb and Oliver 1993). As discussed in the previous chapter, disabled people often have to pay more for accessible technological equipment than their non-disabled peers. Also, 'even "normal" living expenses like food, clothing and travel cost significantly more' (Barnes 1992b: 3). Findings from the OPCS surveys suggested that the extra costs of impairment averaged only around £6.10 per week (Martin and White 1988), a figure which has been much disputed (eg: Thompson *et al.* 1989; 1990). Subsequent research by the Disablement Income Group (DIG) suggested a more credible figure of £69.92 per week (Thompson *et al.* 1990), although this too seems low by present day standards.

DIG spearheaded a major campaign in the 1970s calling for a 'comprehensive disability income' which took into account the extra costs associated with impairment. Their lobbying eventually culminated in a new benefit - Disabled Living Allowance (DLA), which was intended to cover some of these extra costs. It is by no means sufficient however, and impaired people still incur additional expenditure for which

they receive no remuneration. Danielle for example has been unable to get any funding for the extra heating costs she incurs every winter in order to stay pain free:

Danielle

Apparently I can't get no grants to help me with me fuel bills. And over the winter holidays my fuel bill's about three hundred pound... I've got to put meself in debt to have it, because without the heat my back plays up and I'm in agony... But you know, there's no help out there. They give you the bit of benefits that they give you and then expect you to get on with life and try and live off it you know - which doesn't work.

The enforced isolation of disabled people, and the resulting dependence on telecommunications can also create extra costs. Dot for example uses her phone to alleviate her isolation and boredom. She describes being 'never off' the telephone, and has to get her telephone bill on a monthly basis to spread the cost of her bills. Helen highlighted how a comprehensive disability income might enable disabled people to benefit from ICTs:

Helen/fg3

If you look at it from a disability income point of view, then if there was a comprehensive disability income... say for instance in terms of communication, accessing a computer is essential for that disabled person, then that should be covered whether it be there for employment or classed as an aid for living... It depends whether it's classed as an essential or a luxury really.

As the fieldwork demonstrated, many disabled people are beginning to see computer access as an essential. As such, policy changes may be necessary to enable those on low incomes to access the appropriate equipment. The CSDPA could usefully be extended to cover more than just terrestrial telephone equipment, or DLA could perhaps be amended to include a 'communication' component. Any policy which does

not take into account the additional costs of impairment will inevitably leave disabled people at a financial disadvantage.

Computer provision

In view of the extreme financial hardship experienced by many disabled people, it is suggested that 'access to free or very low cost computer equipment is vital... if they are to enjoy the benefits of online communication' (Lamb 2000: 12). Chancellor Gordon Brown has recently announced the government's intention to provide refurbished computers to disabled people and those from other disadvantaged communities (Lamb 2000). Some, like Maude will welcome this initiative:

Maude

Computers now, what's going today... tomorrow they will be obsolete, something else will come. So all right, if they're all going to be obsolete why not let less fortunate people use them, you know to give them an insight into it. I mean you don't have to chuck 'em away... They could be used to give an insight to people and bring them up to the newer models shall we say. 'Cos I mean they're always improving aren't they? Always improving.

It seems unlikely however that all disabled people will be excited by the idea of having other people's cast-offs. Although Danielle is not in a position to afford her own computer, she would still like to have the latest model:

Danielle

For me to get a computer, I want one that would do what I want on it, but be like hip-hop kind of thing - trendy. You know... 'look at my computer, this is what it can do'.

Furthermore, whilst some were adamant that the state should provide disabled people with necessary IT equipment, others, like Curtis were not keen on the idea:

Curtis

If you want anything you should pay something towards things... If you get something for nothing you might not use it. You see my point?

The fieldwork demonstrated that while free or low cost IT equipment may be necessary, it is by no means sufficient. My interviews with those on the COL project revealed conclusively that the mere provision of free computing equipment is not an answer for disabled people. Because of the complexity and unreliability of the technology, appropriate training and backup support are also vital. As one commentator suggests, technology is only 'as good as the human support that lies behind it. Technology itself is only part of the jigsaw' (Johnstone 1998: 140). Max, who knew many of the people on the project through his work, summed up the problem thus:

Max

There's a few people here have got [computers] and I don't think they know what they're doing with them to be honest. So you're gonna need the training. You're gonna need the confidence aren't you? You need the backup. I mean people here have problems with it and they've got nobody to go out and tell them what they're doing wrong!

All participants in the COL project were promised IT training, but this was provided only in a piecemeal fashion with some individuals receiving preferential treatment. It is suggested that a hierarchy amongst disabled people is possible, 'with those most able to articulate their needs, and who present the "socially acceptable face of disability" (without speech problems or physical disfigurement), being responded to more fully' (Harrison with Davis 2001: 129). Kate - educated, articulate and attractive - was high up in this hierarchy. Accordingly, she was sent on a two day word-processing course. Edith however, who left school 60 years previously at 14 years of age, received just one afternoon's training in her home and was in hospital

when her next training session was due. It was never re-scheduled. Hugh's training was also negligible:

Hugh

They've been messing about too much now! ...they promised us they'd learn you how to do it. It would have been a lot better.

The project began in a blaze of smoked salmon lunches and media attention for both participants and organisers. It did not however live up to many of the participants' initial expectations. I heard complaints of money being wasted on expensive hospitality; poor communication with the organisers; lack of consultation with the participants; poor or non-existent training and back-up support; and a neglect of future planning. There were also no plans for any evaluation of the project. There has been a proliferation of pilot projects such as COL in recent years, and a neglect of any assessment of their usefulness may not be unusual. Arguably, their function is less to benefit the 'guinea pigs' selected to participate, than to provide employment and prestige for professionals. Hence, once funding is secured, and salaries guaranteed, the main work is done. This was certainly my initial impression of the project having spoken to those involved. However, whilst Isobel, a development worker, emphasised the high profile that the project had given the local council, she denied that this was simply 'an end in itself'. She admitted that it had not been very well thought out, had been pushed through quickly in the hope of securing EU money, and that no funds had been earmarked for the ending of the project. The project, according to those users I met, seemed to fizzled out gradually, until finally, and with little warning, all Internet facilities were removed from the end of 1998. There must then be more accountability, both to those involved in such pilot schemes and to the wider community, or there is little scope to build on any successes, and avoid making the same mistakes again. As one commentator argues:

There is... a real need to avoid 'pilot fatigue'. Over the last two years a multiplicity of initiatives like Health Action Zones, Personal Advisers, innovative projects, and now the ONE pilots, have been announced - often at a rapid pace

and to a timescale which could militate against a more strategic approach. There is now a need to take stock. (Howard 1999: 12)

Access to appropriate training and support is of course a major issue for everyone who wishes to use complex information technology, hence New Labour boasts of an 'absolute priority to education and skills as the means both of enhancing opportunity and creating an effective economy' (Blair 1994: 6). Disabled people however face particular problems in finding suitable training. Their access needs are seldom met, transport presents difficulties, and their previous level of education is often low. Schooling will therefore be briefly considered before issues of IT training and backup support are discussed.

EDUCATION, EDUCATION, EDUCATION...

Caroline/fg3

You've got to have a certain level of education or vocabulary at least before you can get onto any of these things don't you?

It is well documented that disabled children often leave education with few of the skills that they need to function in society (Oliver 1996a, etc). This was certainly true of many of those fieldwork participants who had congenital impairments. Curtis, Andrew, Helen and Hugh all attended segregated schools. Whilst Curtis claims that his school 'wasn't any different from an ordinary school', he left there without qualifications. He has subsequently gained nine qualifications at a further education college. Helen went on to a segregated college, and has since achieved both undergraduate and postgraduate qualifications. Andrew and Hugh were not so lucky. Both now have difficulties with literacy. As Andrew explained: 'I wasn't at school all that often because I were always in hospital or that'. Hugh attended a series of segregated residential schools until the age of sixteen when he was placed in a residential home. He describes his school days as being hard, with the emphasis on

making his speech and movement more 'normal'. Less attention was paid to Hugh's literacy, and he has been left unable to complete any further education:

Hugh

I don't like courses. I get bored. Because... I can't read. Well I can read, but the words are not big enough. I can read signs outside... but when it comes to a book, the wording jumbles up.

Hugh's constant movements make focusing on words very difficult, and a friend eventually found she could help him to read by sitting on his lap and holding him still. He is still puzzled as to why his teachers did not point this out. Reading was evidently not thought to be a priority for a child with Hugh's impairments.

For those disabled children placed in mainstream schools without the appropriate support - what has been termed 'integration by location' (Jordan and Powell 1992: 87) - there were also problems. Take Max for example:

Max

I got offered to go to a partially sighted school and into the blind system when I was about nine. But... it was like a stigma to the family, so there was no way they'd have me at a partially sighted school. So I struggled through sighted school really. I just made excuses really - 'I haven't got my glasses today' - everything you could imagine! And I stuck to the front of the class - couldn't read the board even then. I struggled! ... So I didn't really have any education really until I was about 27 when I... went to college.

Max stressed however that whilst his education might have suffered, his mainstream schooling gave him 'life skills' which he would otherwise have lacked.

Although most of the participants had not been exposed to computers at school, those like Danielle and Peter, who left school more recently had been trained in IT. In Danielle's case, this was solely because she was classed as having 'special educational needs'.

Danielle

When I was at school... if you got picked to go on the computer, it used to be special needs children. 'Cos I've got dyslexia, which they didn't realise at the time that I might of 'ad dyslexia... A special needs child. Needing extra help. So that's when I first got introduced to a computer.

The use of ICTs in 'special needs' teaching is becoming ubiquitous in today's Britain, has been well documented elsewhere (Blamires 1999; Day 1995), and is beyond the scope of this thesis, focussing as it does on disabled people of working age and above. As Dot points out however, younger disabled people should still have access to computers when they leave school:

Dot

Young disabled... have the computers at school. When they come out of school they're going to miss 'em aren't they? And I think it's something that they should 'ave. They should 'ave training in 'em at school, and I think they should 'ave 'em when they come out. Should be more available to 'em. Even if there's only like library places set up that they can go to and use the computer. I think it'd be ideal... You've got to have somewhere they can go.

Most of the people interviewed had acquired their impairments later in life, and had not therefore been through education as disabled children. Prior to the 1944 Education Act however, access to secondary education was a luxury enjoyed only by a minority. The majority of the older participants then left school at fourteen. They often highlighted how they learned more through employment than they ever did at school:

Frank

I left school at fourteen and I were pretty 'opeless if you know what I mean... And as regards education, I learnt whatever I know at me job, at work. My experience came with working.

As previously discussed however, the majority of disabled people never get the opportunity to learn in a work environment.

Since many disabled people have such a low level of education, the necessity for appropriate IT training is even more paramount. The fieldwork demonstrated however that there is a long way to go before such training becomes widely available, and accessible to all, as will be discussed below.

Further education: Training courses

The complexity of ICT is, as described earlier, an enormous barrier to many people. In the absence of simpler, more self-explanatory systems, training and support services are a necessary addendum to the mere provision of the technology. A new group of professionals is therefore emerging - those with computer expertise. Inevitably, a new form of dependency is also being created for those without such expert knowledge. Training in ICT is high on the government's agenda, with 700 ICT Learning Centres scheduled to provide IT skills to communities, including disabled people (Lamb 2000). If these centres are to be used by disabled people, equipment and venues must be accessible, and accessible, affordable transport must be available. The quality of the training and attitudes of tutors must also be appropriate. These vital factors had been absent from much of the training that fieldwork participants had undergone.

As with 'special education', computers are considered a useful rehabilitation aid for those who have acquired an impairment. Hence Neil first used a computer to stave off the boredom in the rehabilitation unit to which he was sent. Since then he has completed various courses, but is unhappy about the access for wheelchair-using students:

Neil

For disabled people, it said there were more access. You know, there's computers and you can't get to them, or there's no tutors, or there's not enough staff... I asked students every time I had a problem... You go in and there's this computer on the table and that's it. And you can't use it 'cos you can't get to it! [laughter]

Kathleen told a similar story about how she got started. She too has been frustrated by her subsequent experiences:

Kathleen

I was in the process of doing spreadsheets and databases when [college] first of all stopped all transport for over twenty-fives, then the second year they stopped all physically disabled people and opened it up to learning difficulties. So in '98 I went to two courses... and both folded... [it's] a bit upsetting really to stop in the middle of a certificate.

The discontinuation of free transport to college for those over twenty-five is a prime example of institutional ageism. It has had a significant effect on many people, and has particular implications for those facing transport disability. As Melanie (fg3) pointed out, 'a non-disabled person wouldn't have the barriers of transport to get to college'. Both Edith and Martyn were unable to continue their courses because of the expense of getting accessible transport to the college. Edith took the change as yet more proof that she was not young or clever enough to learn about computers:

Edith

After two years they bought it in - I was too old. It's more your young ones innit that go? Not many older ones go though unless they're very brainy, and I'm not.

For other disabled people, their sub-standard schooling and lack of confidence had a knock on effect when they sought IT training. Andrew started a college course, and found it useful to a point,

Andrew

... but I were getting a bit frightened because I 'ad to look for words an' that in books. I 'ad to look for books and I couldn't read them properly. And that's what really got on me nerves. I couldn't understand words. I were scared of going to ask somebody if it were t' right one and that - bit frightening. Bit frightening because if you go and ask somebody and that, there weren't just me who he had to deal with, there were other people in the room.

Several people commented on the lack of time which tutors were able to devote to them. Even those like Max who had received expensive individual training in a work environment, found that the training they received was often delivered too quickly, over too short a time period. This was an even greater problem for people like Andrew who were disadvantaged by segregated schooling, and for older people like Edith who had little experience of computer technology. Edith highlighted how a lack of patience from younger teachers can be a barrier to learning:

Edith

I don't think the young ones have much patience with me to learn it. They can do it. And they show you - 'that's how you do it, that's how you do it!' In fact my granddaughter she's showed me how to ... 'you just do this and you do that'. [I] don't know what the hell's she talking about!... I don't think they have the patience of an older person. It's hard to understand... But the young ones... think if they've told you once then you've got it. I'm afraid I haven't. Not like that.

To avoid the problem of dependence on younger non-disabled 'experts' who may be unwilling to respond to the training needs of disabled and older people, it would be pragmatic to actively recruit computer literate disabled and older people to deliver training themselves. Bill, who had a difficult time at school, told me about the training he had completed since:

Bill

[I] started going [to] other groups which were more independent living groups run by disabled people. So it were like you weren't getting taught by someone who wasn't in the same situation as yourself and hadn't lived through the experience that you're living through. When you've got a disabled instructor, it's like they're living through it, they've been there, they know what they're talking about. So... it's like you take more notice and you learn a lot more things. Well I do anyway!

Finally, as with schooling, further education for disabled people is seldom inclusive, and often means attending a segregated class. The same problems of low expectations, substandard teaching and ghettoisation are there for adults and children alike. Curtis has attended a number of computer training courses since leaving school, all of them segregated until the one he was enrolled on when I interviewed him. He said this one was much better, because 'When you're in with disabled people they're not doing what I can do - they're always doing the basics'. Andrew had also enjoyed attending an integrated course:

Andrew

I think it's good in a way because they'll give you a hand if you're stuck... And it's vice versa - if they're stuck, we might be able to 'elp them.

Segregation is not the way forward for a society that aims to include all of its citizens. As Oliver (1996a: 94) suggests, in disabled peoples' continuing struggle for inclusion 'special, segregated education has no role to play'.

The ultimate in segregated provision is of course the resource centre for disabled people. It was within this context that many research participants first learned to use IT. This training however was very dependent on the skills and motivation of particular resource centre workers, and often the computers stood unused. The ethos of the centre also had an effect. The manager of Airedale Resource Centre for example, commented that IT training was not part of their role, as it was something that could be delivered elsewhere. The local council has recently adopted a set of

Aims and Objectives of Resource Centres used by disabled people, in an attempt to move away from the more traditional, dependency creating day care provision described by Barnes (1990). These changes have been very difficult for many of the older people who have used the services for years (Peacock 1997), perhaps because of problems with their implementation, perhaps because of the adoption of a new set of age restrictions. At Colliers Resource Centre, I was often told about these adverse changes:

Maude

Really this is a resource centre not a day centre, and they don't care for my age group. No they don't care for my age group. Only seeing as I've come for so long - all right I can stay. They won't take my age group now.

Edith

It's changed so much has Colliers. They're self-centred. It's not a Colliers for old people any more it's a kind of youth centre... I think the most you can come to now [is] till you're 60 - 65 or 60 - and then you have to leave.

As well as decrying this age discrimination, Edith was particularly critical of the lack of computer training at Colliers:

Edith

There's no one bothered to teach you. They can't be bothered.... It's gone down the drain like anything.

At Stanmore Hill, participants were much more enthusiastic about the individual tuition and support that they were receiving from Kenneth:

Andrew

It were Kenneth who learnt me about the Internet more than 'owt else, and this is why I picked it up so quick... It were because I just 'ad like one person to talk to really. I

didn't 'ave anybody else telling me what to do and that, and it were a lot easier. I feel more relaxed on Internet when Kenneth is there... Just for words I usually go down to other people, but if Internet crashes, sometimes I ask Kenneth 'ow you do it an' that. He tells me. He'll go over it and he'll go over it again.

Whilst this kind of one-to-one tuition has many advantages over the training offered by college classes, there is of course a danger of creating dependency on individual resource centre workers, in a profession with a relatively high staff turnover. Since the completion of the fieldwork, Kenneth has found other employment. There appeared to be no other staff with his enthusiasm and computer expertise who could perform quite the same role.

Teaching yourself and back up support

According to IT-for-All's survey, whilst 26% of people learned to use IT at work, and 17% at school or college, 28% of the computer using population learned on their own using manuals (DTI 1999). Not everybody is comfortable using manuals however, and as Helen commented:

Helen/fg3

The title of those to start off with indicates people's attitudes, like for instance 'Microsoft Office for Dummies'. That's disablist language to start off with!

Bill however bought the offending manual and found it very useful:

Bill

It were called 'Learning for Dummies'... It's really good. Because say with computer language it breaks it down, and it talks your language... that really helped me a lot. I didn't mind being called a dummy 'cos I were!

Inevitably, for those who are learning and using IT in isolation, back up support is a major issue. What happens when something goes wrong? Whilst those using computers at work or college usually have somebody on hand to help out, those learning at home are in a very different position. Some people had computer literate friends to help out when necessary, but many are not in this position, particularly older people like Edith:

Edith

My friends don't have a computer. So I've no one to ask really how you do it. I've got to fathom it out myself.

Some were concerned about the dependency that was being created through complex and undependable IT equipment, and inadequate training. As Caroline pointed out,

Caroline/fg3

I think it leaves us in a situation - people like me who really only know it at one level - if you don't know friends or somebody up the road, you're then having to rely on the experts etcetera. So yet again, here we are relying on another bunch of experts.

IT help lines are often expensive to call, and there is no guarantee that those answering calls will be sensitive to callers' differing levels of knowledge. As Helen commented:

Helen

I think sometimes when people know a lot about computers and software they forget that other people don't... And if they think you've got a bit of knowledge, they always assume that that is more, and that they don't need to go over the basics again.

Participants in focus group three suggested ways in which these help lines could be made more accessible:

Caroline

Well backup support lines... should be prepared to talk to people not patronisingly and spend time with us, and you shouldn't have to pay for that phone call, or only a local rate or whatever.

Melanie

They should have a free phone number. There should be a free phone number for everybody because if you're non-disabled and [you've] not got a lot of know-how about computers then it's going to take time and effort.

Caroline

I mean if you're asking who should pay for that, Tony Blair etcetera all on about how they want us all to be computer literate [should] put their money where their mouths are and do something practical and fund these lines.

(fg3)

Martyn was adamant that ICTs could make life better for disabled people, and that:

Martyn

The only way it would be worse for somebody is if they didn't get the support they needed and something went wrong then they would get frustrated because they didn't know what was happening. Now I would say that every disabled person who has a computer should have support. You should have support.

Kathleen was in agreement, and highlighted the particular importance of support for older people:

Kathleen

As you get older, technology gets more frightening and I think it needs to come along with help somewhere along the line. You know - you can't just stick a disabled person with a computer and get on with it. They need some outside help. So being

computerised is not going to stop everything because everybody'll need help along the way.

A lack of support, or inappropriate support can have significant effects on self-esteem, as will be discussed below. First though, a note of caution about the current obsession with education:

Twenty first century basket-weaving: Education for what?

Whilst issues of training and support were frequently raised in the fieldwork, it may not always be the panacea that the government suggests. New Labour critic David Willetts (1996: 70) rightly points out that 'there is no reason why greater equality of opportunity should lead to greater equality of outcome. The capacity of education and training to generate equality is... much exaggerated'. Even Blair's favourite sociologist, thinks 'the idea that education can reduce inequalities in a direct way should be regarded with some scepticism' (Giddens 1998: 109-110). The current governmental enthusiasm for IT training is essentially a strategy aimed at changing individuals to better fit into the new digital world of the twenty-first century (Blair 1994). This could further disable many people, who are, through no fault of their own, unable to benefit from such training. As Danielle commented, 'it don't matter how much training you 'ave, sometimes you are baffled about it'. Edith certainly appeared baffled despite having been on IT training courses for two years. As she told me: 'everything they taught me I've forgotten.' Whilst her training was not entirely appropriate, it may be that any training would have had a similar effect. Education, according to Illich (1977: 28) is 'the major generator of a disabling division of labour'. Hence education in IT may ultimately create further divisions within the disabled community, and establish a further professional group of experts who will serve their own interests first and foremost.

Disabled people are frequently enrolled on training courses which do not improve their chances of subsequent employment, something that initiatives such as the New Deal will perpetuate. False hopes are being raised by this process, and 'the cumulative

effect of repeated and inappropriate training courses becomes disabling in itself (Rabiee 2000: 29). The current governmental emphasis on IT training may then represent little more than a re-invention of the old "'basket-weaving" therapeutic approaches' of the past (Sapey 1999: 631).

INTERNALISED OPPRESSION AND SELF-CONFIDENCE

As Carol Thomas (1999: 49) suggests, there are various 'psycho-emotional dimensions of disablism' which impact on people with impairments. Others refer to 'internalised oppression' (Mason 1992; Rieser 1992): 'the feelings of self-doubt, worthlessness and inferiority which frequently accompany the onset of impairment' (Barnes *et al.* 1999: 177). These psycho-emotional aspects of disablism can 'indirectly act to "restrict activity"' (Thomas 1999: 48), and hence create yet more barriers to many people's beneficial use of technology. Even the telephone was difficult for some people to pluck up the courage to use:

Andrew

When you're on t' phone you just get muddled up [about] what you're saying. I do anyway. I don't know about other people. Some people have got confidence on phones. I've not.

Computers gave Andrew even more problems, especially when he first used one:

Andrew

I were terrified! Absolutely terrified! I were scared just in case I got 'owt wrong more than 'owt else... When I first went on t' Internet I were nearly trembling.

Andrew's confidence was probably affected by his low standard of education. Education is not however the only factor at work in determining people's perceived

abilities in relation to technology. Kate was educated to degree level, and still admits to being scared of computer technology. It may be that factors such as gender and age play a role (see below). Alternatively, it is possible that some are poorly equipped to deal with such technology, much as those with dyslexia are poorly equipped to deal with the printed word. Perhaps this will become a significant impairment in the future.

Both Bill and Robert had bad experiences when they first had computers at their homes. Both eventually asked for them to be taken away because of the psychological damage they felt they were creating:

Bill

I were really scared of it. I were scared of breaking it. I were scared of ordering summat on the Internet and not being able to pay for it. Really spooked me up in a big way.

Robert/fg3

It was mind blowing the first time I went on one... I just kept making mistakes and every time I made a mistake it just got worse and worse... It just got to the stage after the end of the six weeks I said come and take it away please. My mind had gone.

Internalised oppression, and the low self-confidence it can create, can also prevent disabled people from accessing computers in public places, and from taking up further training. Disabled people's organisations often provide assertiveness training to help disabled people overcome such restrictions, something that fg3 joked about:

Caroline

Even if you make anywhere that provides them publicly, you make the computers there accessible... we've still got the hassle of getting there, or having personal assistance to get you there, or personal assistance when you are there. You're still gonna have that. So you're still going to have more barriers than a non-disabled

person in the same position... social skills! If you've got to battle your way in and say 'my turn next' [laughter]

Helen

Also people's attitudes towards you when you're in that place as well quite often prevent you from going.

Robert

Makes me more determined to go!

Caroline

You've 'ad assertiveness training! [laughter]

(fg3)

However, whilst society continues to perpetuate a 'personal tragedy' model of disability, many disabled people will struggle with feelings of inadequacy, and hence be reluctant to pursue access to complex technological systems. This may also be true of other oppressed groups. The stereotypes associated with both older people and women for example, are of technological incompetence. It is possible then that further barriers exist to prevent disabled women and older disabled people from accessing IT. The type and onset of impairment may also play a role. A brief consideration of these other dimensions of difference therefore seems appropriate:

TECHNOLOGY, DISABILITY AND DIFFERENCE

Old and past IT? Disability, older age and technological access

It is argued that the rapid pace of technological innovation 'renders the accumulated knowledge and skills of older people redundant, contributing to their devaluation' (Dowd 1980 cited Arber and Ginn 1991: 34). Hence Maggie Kuhn, founder of the Gray Panthers, highlights the stresses of 'growing old in a technological society' (1984: 9). Younger participants were often optimistic about this society and were

pleased to be living in an age where technology was on the ascendancy. Older people like Maude were less impressed:

Maude

I call it an automatic world. That's the future... sometimes I shudder when I listen to 'em speaking. I think 'oh crikey Moses, I don't like that'. And yet I've no say in it! It's all going to be done whether I like it or not... there's too many against you. It's what I would call a free and easy way today. All these machines doing all the work for you. You just sit there and prod a button and it comes up for you... Should anything happen, and all these machines break down, where would you be? 'Cos I mean you've not learned anything, you've just gone by that machine. You've not learned anything. I mean we learned by our hands, which I think is important - use your hands. But that's the way of the world. Nobody wants it today you see... I'm glad I'm on the way out the way things are shaping! Oh yes - glad I'm on the way out. All this cloning bit and all this 'ere modified stuff that you're eating... I don't think you're free at all today... The youngsters won't think that way today. They only know this way. I mean I can tell different. I have values and I can weigh the values - pros and cons... All these machines are taking over.

Maude, like several of the older participants admitted that she felt left behind by modern technology, although Dot claimed 'only thing I feel left out of is money to be able to afford it!'

IT-for-All's survey revealed a striking demographic profile of those who were and were not enthusiastic users of technology. In the style of much 'diffusion research' (Rogers and Schoemaker 1971) the population was divided into five categories: enthusiasts, acceptors, unconvinced, concerned and alienated. Older people tended to fall into the latter groups. Only 6% of 'enthusiasts' were over the age of 65, compared to 37% of those deemed to be 'alienated' (DTI 1999). What of the older disabled people who participated in this study?

All but three of the interview participants had used IT at least once. All three were over 65 years old. Seven interview participants had never used the Internet. All were

aged 49 years or above. Hence just two of those who were over 65 had ever used a computer, and only one had accessed the Internet - Edith, aged 74, who was part of the COL project. Maude, the oldest participant at 78 years old, once attended a one-off IT course, and was definitely interested to find out more. Edith however, used her computer mainly to play games of patience. She was unconvinced that information technology would catch on with older people since none of her peers were interested, or could see any point in her having a computer. She thought that a lot of older people would not put up with the mess of the electrical wires, and that they were too complicated for them to be bothered to learn. She did however think they were important for younger people:

Edith

Kids absolutely love them! But... [they're] too complicated for the old ones... they can't understand them. They don't want to do. Kids are bought up with them from school aren't they? If I'd have been brought up with them I'd have loved it. I love it now, what I can do. But the older people - I don't think they're interested... 'Cos it's something new isn't it, they've never had before? They don't like the challenge of it.

Agnes, at 74, also had reservations about computers:

Agnes

I always think, well I've had me time and is it worth it to get one of these things you know. I think they're not for me these things - would I be able to use it and things like that?

She would not consider buying a computer: 'I think I'm too old now... Unless I live to be a hundred! Then I might!'. She was not however averse to trying one: 'I'd have a go at 'owt once. If I can't do it, well that's it'.

It seems though that chronological age is not a barrier in itself. Several people mentioned that younger people were at an advantage in that they had more experience of computer technology through the education system.

Maureen

It's more for the young disabled because when they're at school they'll be taught how to use a computer - like my grandson. He can use a computer - up to a point. But such as me, I'm not saying that I'm too old to learn, but I can't grasp anything like that.

Rose

Not being brought up with a lot of this technology that youngsters are brought up with are we?

(fg1)

Others just 'couldn't care less' about computers. This seemed to be a pragmatic decision based on the perceived use-value of the technology, and the effort involved in learning to utilise it. As Kate, quoted by Scherer (1993: 133) suggests, if people have managed without a computer for the first fifty years of their life, 'the device doesn't make a significant enough difference to warrant all that effort to learn to use it'.

Whilst ICTs were seen as an invaluable business tool, and something which might benefit younger disabled people or those with severe impairments (see Chapter Four), many saw little point for themselves. As Esther (fg1) commented: 'it's probably more use to the younger disabled than it is to people our age'. Nancy expressed similar sentiments:

Nancy

To be right honest, I can't see what good it's going to do for me. Younger end...But for me I just can't see... so why sit there and rack your brains and struggle over something that you're not bothered about... I mean if it were going to 'elp me to get a job, if it were going to 'elp me in my work or anything like that - yeah. But as it is now - what for? Why?

It has been suggested that much of the technology being developed is inappropriate for those outside work, and that this may compound the lack of access for unwaged people (Cassell 1990). Hence, whilst some younger disabled people saw IT use as

having potential future benefits, perhaps when seeking employment, many of the older people who participated in the fieldwork were in a different position. As Nancy asked: 'Who's going to employ us at our age, when there's hundreds of thousands of young uns out of work?' They were often adamant however that computers should be more readily available to younger disabled people:

Agnes

I mean I've 'ad my life, but young ones, a lot of young uns that are disabled, I mean they can carry on if they have the information there - the computers there... Now a lot of 'em they can't talk and that, but they can learn off them things. I mean there's a lot of people 'ere, a lot of disabled people - they're all right in their 'ead, but not in their body. That's why I think they should be made available for t' younger end of disabled people.

Is IT a man's world? Disability, gender and technology

Technology is said to be 'a vital aspect of modern patriarchy', which has systematically excluded and alienated women (Arnold and Faulkner 1995: 22). It seems this still holds true. Recent figures suggest that whilst 57% of all British men have accessed the Internet, only 45% of women have done so (National Statistics 2001). I fully expected to uncover similar differences in disabled men's and women's accessing of IT and the Internet. However, whilst women were more likely to voice concerns about technology's complexity (see Chapter Four), and often used technology in different ways (see Chapters Seven and Eight), this study showed little in the way of gender disparities in computer access. The men interviewed were only slightly more likely to have used IT (10 men to 9 women) and accessed the Internet (8 men to 7 women).

Cockburn (1994: 41) suggests that 'ineluctably, technology enters into our gendered identities'. So too does disability. Disabled women and men are often perceived as unable to aspire to 'normal' gender roles (Fine and Asch 1988; Morris 1993b; Shakespeare 1996b), and hence experience gender as an oppressive social

construct (Morris 1993b). Contemporary Western femininity has 'involved the constitution of identities organized around technological incompetence' (Cockburn 1994: 41). Perhaps then the disabled women interviewed had 'not been "trapped" by many of the social expectations feminists have challenged' (Fine and Asch, 1988: 29), such as the expectation of technological incompetence. As described in Chapter Three, disability may also affect men's relationship with technology. Whilst technology is perceived as 'the doings of men', to be a man in Western society is to be a 'muscular', 'hands-on' type (Cockburn 1994: 41). Impairment does not fit into this equation. Bill for example considered training as a mechanic, but eventually rejected the idea, thinking 'who's gonna employ a disabled mechanic in a wheelchair?'. Gender then may play a significant part in both disabled women's and men's relationships with technology. This area undoubtedly merits further study.

Not feeling up to IT: Impairment effects and technological access

It is suggested that disabled people may view technology differently depending on whether their impairments are congenital or acquired. For those disabled from birth it is argued, technology may open up whole new worlds, whereas for those disabled later in life, it will never give them back what they have lost (Scherer 1993). Whilst such thinking seems to perpetuate a view of impairment as personal tragedy, it may in part explain older people's ambivalence towards technology. Of those over sixty-five only Maude was, in her words, 'born a cripple'.

Type of impairment may also affect disabled people's desire to access IT. Learning to use technology is perceived to be a drawn-out, time-consuming process which may be ruled out because of impairment effects (Thomas 1999):

Norris

[It's] like learning to read or cook and all that, but with this you've got to do it more and more haven't you? No end to it really is there?

Ray

I know it's a never-ending process.

Caroline

That's another point - time - having the time! And I don't know about anyone else but managing my impairment takes up a great deal of the time that I've got for the day - sorting out the body. So the amount of time you've got left to do anything else, never mind learning something new is not a great deal.

(fg3)

Impairment then may have a major effect on the time and energy left to pursue other activities (Crow 1996). The perceived use-value of a technology might then be balanced against the time and energy required to utilise it effectively. For many impaired people, the ends may not seem to justify the means.

Questions of what uses disabled people have for information technology will be addressed in subsequent chapters. It is important to remember however that not all disabled people want to use this kind of technology, or see any benefits in doing so. They must not however be blamed for their lack of interest. As one commentator points out,

The most ironic aspect of the many technological projects that fail because of a lack of any real understanding or dialogue between professionals and people is that the failure is often blamed on the people. They are said to lack willingness to change and sometimes sociologists are brought in to study the cultural blockages or vested interests that are assumed to be opposed to progress. Yet the real problem is often with the technologist, who has never sat down with people to discover what their lives are about and what they want and need. (Pacey 1983: 150)

SUMMARY

Communication systems can transcend the spatial barriers which we all increasingly face. Consequently they are assumed to hold enormous promise for those who have difficulty leaving their homes or travelling. Many disabled people and older people face numerous barriers to leaving their homes, and are hence very dependent on

communication systems. Rather than prioritising access to ICTs however, they frequently show more enthusiasm for making the outside world more accessible, so that they have choice in how they make contact with the world. Many are concerned that policy makers might have other priorities, and thus limit their choices by funding technology over more meaningful social change.

Access to ICTs is however seen to be increasingly important, and radical changes are needed before disabled people will be in a position to utilise this technology beneficially. At present, as well as facing barriers to leaving their homes, disabled people face barriers to accessing ICTs. These barriers will not be fully removed until the continued segregation and oppression of disabled people is challenged and rectified. Access must be secured on all levels before disabled people will be fully included in twenty-first century society.

As we have seen however, accessible technology can be deployed in ways which can liberate or oppress. We will now therefore concentrate our attention on the use-values of communication systems for disabled people, and the needs which they are said to satisfy. We will begin by considering the basic human needs of physical survival and personal autonomy, and whether these are satisfied effectively through the use of communication systems.

CHAPTER SIX: AUTONOMOUS LIVING IN THE VIRTUAL COMMUNITY

This chapter will examine the ways in which disabled people living in the community use their communication systems to enhance their peace of mind and security - their need to avoid serious harm; and to enable greater autonomy - 'the capacity possessed by the individual self for choice' (Jary and Jary 1995: 35). The needs for physical survival and personal autonomy are not 'special needs' peculiar to disabled people. These needs are shared by all, and are basic to human survival (Doyal and Gough 1991). As discussed above many people's needs are met automatically, whilst disabled people's are not. The disadvantage that they experience may make it particularly difficult to satisfy even these basic needs. The concepts of physical survival and personal autonomy as they relate to disabled people will be briefly considered. The use of communication systems as a key component of 'community care' will then be examined. Finally the use-value and potential abuse-value of telephones, community alarms and 'smart homes' will be discussed, as will the use of communication systems outside the home.

PHYSICAL SURVIVAL

Vulnerability is part of the human condition. We are all 'capable of being wounded or susceptible to injury' (Brearley *et al.* 1982: 26), since human beings 'are by nature frail creatures' (Finkelstein 1998: 29). Finkelstein (1998: 29) proposes that 'the natural vulnerability of human beings has significantly shaped the development of all the machinery of modern social life', and is critical of the, until recently, 'unchallenged dogma: that the possession of impairment leads to social vulnerability'. This dogma is often unchallenged even today. We are told for example that slower reaction times, and deterioration of sight and mobility can make older people more prone to

accidents (Help the Aged 2000), despite the fact that accidents are crucially related to environmental factors (Brearley *et al.* 1982). It is suggested that the tendency to view those with impairments as vulnerable is bound up with the fact that our needs are seen as separate from those of human beings in general. Through having our assumed needs and aspirations attributed by others, we are 'falsely identified as a uniquely vulnerable group in need of care' (Finkelstein 1998: 30).

Whilst the presence of an impairment does not automatically create vulnerability, there is strong evidence that disability and vulnerability are linked. Research into the abuse of disabled people for example argues that the disadvantaged circumstances of disabled people *do* make them more vulnerable to certain kinds of harm (Calderbank 2000; Kennedy 1996; Shakespeare 1996b). Likewise, accidents are a major cause of injury and death for older people, and there are 'specific hazards and deficiencies' in their lives which make them vulnerable as a group and 'which, for a substantial minority, create imminent and serious danger' (Brearley *et al.* 1982: 136). These hazards are not biological, but social, and include lack of money, lack of support, and unsafe, inappropriate housing.

The barriers which serve to keep disabled people prisoners in their own homes, may also place their physical survival at risk. If for example they cannot easily escape from their homes, what would happen in the event of a fire? If their homes do not have the appropriate adaptations, will the likelihood of household accidents increase? Will their assumed vulnerability make them easy pray for opportunistic intruders? Will the dependency relationships in which they are often placed make them more vulnerable to abuse? Some of those interviewed certainly viewed themselves as particularly vulnerable. Take Max for example:

Max

[If you're] blind... in a way you're more vulnerable than a lot of disabled people. If you've got a guide dog especially, you're telling everyone you can't see. You can't hide it.

Bill described how he is often placed in vulnerable positions where he has to trust others, and that this trust can be abused:

Bill

I've a lot of trust in people. I guess that's one of the main things you 'ave to do if you're disabled. If you want help or you ever need help you've gotta put your trust in a lot of people. And sometimes it backfires which I find now. Some people take advantage any way they can.

Whilst even our most basic needs remain unsatisfied, it seems that disabled people may well be more vulnerable to 'physical harm'. This is not due to our impairments, but a result of our disadvantaged position in today's society. In the absence of meaningful changes to that society the need for a 'safety net' is increased. The continuing segregation of disabled and older disabled people, the enforced restrictions on their mobility, and the push for cost efficient 'community care' have made them increasingly dependent on the safety net provided by communication systems, as will be discussed below. Firstly though, the concept of autonomy will be considered.

PERSONAL AUTONOMY AND 'INDEPENDENCE'

Autonomy as a concept has enjoyed a recent resurgence, with many theorists using the word to refer to quite different things, and frequently using the concept in a very broad fashion. Dworkin (1995: 359) confesses to being unclear about the reasons for this 'increased reliance on the idea of autonomy', yet it seems to sit quite happily with the current ideology of neo-liberalism. Alan Scott (1995) suggests that a key feature of new social movements is their stress on autonomy. Hence, for Shakespeare (1993: 261) the 'central values of the disabled people's movement are autonomy, integration and independence'. The concept of 'autonomy' is about exercising choice and self-

determination, and as such is almost indistinguishable from the disabled people's movement's idea of 'independence' (see Chapter Two). As Kate insisted: 'independence isn't about being able to do it yourself. Independence is about making the choice - having the same choices that other people have'. Whilst Kate was very clear about what independence meant to her, it was not always clear what other fieldwork participants meant by the term because of its widespread conflation with self-sufficiency. Frank and Patrick for example had conflicting ideas about the subject:

Frank

I mean even people that are really bad, that can't get out, there's facilities there today for someone to do it for them i'n't there? There is other ways of getting on with these things.

Patrick

You've got to rely on other people doing it for you haven't you?

Frank

Well at times you've got to rely on people doing some things for you. At times people in wheelchairs have to rely on someone pushing them haven't they, and opening doors for them?

Patrick

But if you want to be independent, you want to be able to push things yourself. You can't always rely on people.

(fg1)

Participants often claimed that communication systems made them more independent, despite the fact that this independence was sometimes gained at a price - increased dependency on often unreliable technology, and on a new breed of technological 'expert' (see Chapter Four). Furthermore, communication systems often took a role in disabled people's lives which would previously have been filled by other people. This was frequently seen as promoting 'independence', although arguably it would not increase the capacity for choice, and might also create further

isolation. It is suggested then that whilst 'the immediate benefits of aid-use may be welcome, the long-range ramifications for the user could be total dependence on an assistive device prone to malfunction and breakdown' (Cavalier 1987: 136). Similarly, Georgia McMurray (1987: 148) introduces a note of caution when she asks:

Do we wish to reinforce an individualistic atomistic society where disabled people are even less dependent on family and friends? Is independence to be achieved at any cost? The promotion of machines as technological advances for the disabled will move us in that direction.

However, many disabled people welcome the opportunity to carry out tasks unassisted by others. They are frequently dependent not on family and friends, but on a vast and ever changing array of professional helpers and strangers. Hugh for example has round-the-clock assistance in his new bungalow from a variety of different people, and dislikes the fact that he never knows who will be coming next. As described above, disability often forces those it affects to put their trust in strangers - something which many would rather avoid. Perhaps then dependency on a machine is sometimes preferable to dependency on a stranger. Better the devil you know? Jim (in Scherer 1993: 33) highlights a further way in which machines might be more dependable: 'People may or may not be there when you need them, but devices are still in the place where you last used them'.

Autonomy, or as the participants in the fieldwork were more likely to call it - 'independence' - was a major theme throughout the fieldwork, and underpins much of the discussion in subsequent chapters. In this chapter, autonomy will be discussed in terms of so called 'community care technologies': systems which purport to assist the basic tasks of daily living in the home. Specifically use of telephones, community alarm systems and environmental control systems or 'smart-housing' will be examined. The increased autonomy that the use of mobile communications can provide will also be considered. Firstly though, there will be a brief discussion of the increasing provision of communication systems as a key component of 'community care'.

CARE IN THE VIRTUAL COMMUNITY?

A basic theme in the work of Ferdinand Tönnies (1957), captured in his *Gemeinschaft/Gesellschaft* distinction, was the loss of community and the rise of impersonality. Whilst close-knit communities are often 'suffocatingly homogeneous and intolerant of difference' (Hoggett 1997: 14), the concept of community is still associated with romanticised notions of 'social support, intimacy and security' (Jary and Jary 1995: 101), things that many feel are lacking in today's society. Hence, helpful neighbours have been described as 'a vanishing species' (Illich 1977: 27) and the family is also said to be less prominent in many people's lives (Wolff 1983). Community is a 'continually contested term' (Hoggett 1997: 14). As Marion Barnes (1997: 5) explains:

the contemporary use of the term is coloured by historical associations which have lost their meaning within present-day circumstances... As urban development and industrialisation started to change the nature of the circumstances in which many people lived, the notion of community came to represent the Golden Age of an assumed past in which communal relationships based on personal ties served to bind people together for their mutual benefit.

Third way politicians, inspired by writers such as Etzioni, are keen to rekindle this mythic, lost community, so that for 'New Labour "community" has become what "class" was for old Labour' (Hoggett 1997: 13). New Labour's version of a good community is thus said to be one which 'pulls itself up by the boot-straps that the system denies it' (Sivanandan 1997: 294).

Older participants in the fieldwork often romanticised the community spirit of the past. Since ageism makes people feel redundant and out-dated as they grow older, it is perhaps inevitable that older people will 'look back nostalgically to those times when [they] were wanted, useful and felt bang up to date [and] believe that in those days we respected our seniors in a way that no longer applies' (Bytheway 1995: 16). It is also perhaps inevitable that when older people get together with their peers, they will bemoan the current state of the community. Take the 'Memory Lane' group at Colliers Resource Centre:

Sylvia

Your families are more widespread now...

Frank

I mean, the trouble nowadays is you've got no neighbours have you like you used to have.

Sylvia

Your family's all away.

Patrick

They don't want to know now do they? They don't want to know.

(Fg1)

Many of those who participated in the fieldwork were living alone, often in sheltered housing 'ghettos'. Whilst some had frequent visits from family members, others had little contact with their families and contact with neighbours was often minimal. Some were forced to leave their previous homes in favour of more accessible housing in new locations, and had made few links with their new neighbours. For many, the segregated resource centre seemed to provide a sense of community membership which would otherwise have been lacking. These centres seemed to provide 'communities of identity', membership of which was of more significance than community membership 'defined by locality' (Barnes 1997: 157):

Joyce

We're all in t' same boat, so we all understand each other. I don't think any of us have ever fallen out have we? We've had conversations 'aven't we? We've never fallen out through it. We've sorted it out, but we've sorted it out between us. As I say we're all in the same boat so we all understand each other. But when you go out of 'ere, you can have an argument with someone because they don't know what you're... on about, where we all do. We're like a big family here. There's something wrong with every one of them.

Janice

Speak for yourself! [laughter]

Joyce

But we all try to 'elp each other. If we could 'elp somebody in some way we'd do it.

(fg4)

Few though live in traditional *Gemeinschaft* communities, which would arguably provide them with the means of satisfying their basic need for physical survival and security in the home. Other means of satisfying such needs must now be deployed. Whilst geographic communities are said to be in decline, with the aid of communication systems we can now be part of 'the global electronic *Gemeinschaft*' (Robins 1995: 151). Hence we increasingly look to our psychological neighbourhoods (Aronson 1971) or virtual communities (Bowers 1996; Rheingold 1994), to satisfy our basic security needs.

'Care in the community' would arguably not have been possible in its present form without telecommunications. More expensive, labour intensive means of support would have had to be deployed. As discussed previously, this kind of 'technical fix' is often unwelcome amongst disabled people, yet is increasingly the solution favoured by financially stretched service organisations, especially in light of demographic predictions. 'Community' then may simply have become a 'metaphor for the absence or withdrawal of services by the state' (Hoggett 1997: 10). As one commentator suggests:

For organizations whose concern is with the quality of life and services, the recession has forced difficult decisions, often dilemmas, between maintaining staffing levels or investing in more modern technologies. The future use of IT has got itself tied in with economising, the idea that it can enable services on the cheap, and this has spread into the design of software to serve financial rather than human purposes. The association of IT with reduced spending on the human services has, if anything, increased the level of resentment and suspicion that exists about technology based solutions. (Glastonbury 1993: 2)

Nonetheless, many are optimistic about the potential of communication systems as a key component of future community care provision, enabling institutionalisation to be avoided, or at least delayed (Evandrou 1998; Taipale 1993). Technology it is said, is

an *essential* solution to the much vaunted crisis in the welfare state - 'the crisis of diminishing funds and increasing need for care' (Taipale 1993: 31).

Not all of these so-called 'community care technologies' have been specifically designed for such a purpose. The telephone is the most ubiquitous of these systems. The very act of telephoning has been described as a 'form of care giving' (Rakow 1987: 176; cited Moyal 1989: 294), and the importance of the telephone in reducing the institutionalisation of both disabled (La Rocca and Turem 1978) and older people (Moyal 1989) is often highlighted. Whilst other technologies are now said to perform a similar function, the primacy of the telephone for disabled people living at home is already recognised in UK legislation in *The Chronically Sick and Disabled Person's Act* (CSDPA). The Act highlights the importance of the telephone to summon assistance in an emergency especially for those who live alone, and allows local authorities to financially assist disabled people to obtain and use such equipment (Knight and Warren 1978).

Since recent community care policies mean that many disabled people are now living in the community, often alone, often with limited support and with numerous restrictions on their mobility, they become 'heavily telephone dependent' (Moyal 1989: 296), with the telephone a vital link to the outside world. Previous studies have highlighted the importance of the telephone as a means of satisfying the basic need for physical survival and security, especially amongst older people (Aronson 1971; Drake 1999; Moyal 1989). There has been less attention to the role of telephones in satisfying younger disabled people's security needs, although it is suggested that they may serve a similar function (Lifchez 1983). In line with these studies, the fieldwork demonstrated that the primary use-value of the telephone was in satisfying research participants' basic human need to avoid harm. The findings will be discussed below.

SENDING OUT AN SOS: THE TELEPHONE AS A 'LIFELINE'

Caroline/fg3

Safety. I know that if I need to summon help for whatever reason, then I can do that. That's my number one reason for having a phone.

Joyce/fg4

A lot of us, you never know what's going to happen during t' night, and you've got help there straight away... you go to pick the phone up and you've got 'elp.

All of the disabled and disabled older people who participated in the fieldwork had household access to a telephone. Many described it as a 'lifeline', without which they could not function. Whilst some highlighted its importance for instrumental purposes such as getting information (see Chapter Seven), or for intrinsic, sociable calls (see Chapter Eight), the majority saw its use in an emergency as its main benefit. Even those facing barriers to using the telephone, attached importance to its use-value in an emergency. Jessica for example has a speech impairment and hates using the telephone. Although she does not have a terrestrial phone line, she has a mobile phone in case of emergencies. John has no oral speech at all, but has devised a system whereby he rings his family, then bangs on the table in front of him if he needs help when they are out of the house.

Many of the disabled people I spoke to had a telephone in more than one room, so help could be summoned from various locations in the home. Others had purchased cordless phones for the same purpose. Danielle was one of several participants with mobility impairments, who carried a cordless phone around the house with her. She was adamant that it was not a luxury, but an essential:

Danielle

I've got a cordless. And the reason why I've got a cordless phone is because I can carry it around with me... And with my back, I can't really predict when I'm going to

like collapse. And that's the reason why I got a cordless phone... It's not something [where] I said I want to be trendy and have a cordless phone, you know. It is a need.

Most saw the telephone as being particularly necessary for disabled people, older people, and those living alone:

Patrick

In my honest opinion, disabled people couldn't do without phones... It's a lifeline. If you're in a bit of difficulty and you want some 'elp, first reaction, you just go to the phone, and you ring for somebody and you get some help.

Nancy

Well I think that for older people [telephones] are a necessity. They can call for their family, they can call for t' doctors, they can call for someone to 'elp if they fall... I think for t' elderly they're a necessity. They're not a luxury. Summat that's needed.

Maude

It's a necessity for the older people. I think it is. As you get older you'll find that out!

Nancy

Well, it's your lifeline for outside i'n't it? It's your connection.

Hugh

If you're on your own you need one just in case summat happens... Yeah - fire brigade, ambulance, police, they can come. Without a phone there you'd be panicking.

The reasons for this increased dependency on the telephone were largely seen to be social. Some for example considered the 'telephone dependency' that being 'housebound' created:

Patrick

Well t' telephone is a lifeline to me. It is a lifeline. I can't do without a telephone... if you need 'elp... if you need to get in contact with people. It's your lifeline! When you hear of how they're stuck in - housebound. If I weren't coming [to Colliers] I would have been 'ousebound. So telephone links you to the outside world really. So I need a phone. It's an essential to me, yeah. You know, your link to the outside world.

Graham/fg2

It might sound silly I know, but I'm more fortunate than some people to get out. I don't depend on [the phone]

Likewise April highlighted how her use of the telephone changed when she became disabled, and was no longer able to drive. The phone is particularly important to her now,

April

for help if I [need] help. I mean especially where we are, 'cos we're very isolated where we live... I suppose before, it were just sociable reasons before, because I could always jump in me car and go somewhere if I needed to... get help or anything.

All the research participants saw the telephone as an essential, especially since the barriers they currently face often make summoning help in other ways an impossibility. As was discussed above, it could also be argued that these barriers make them more vulnerable to harm, and therefore their need for a 'safety net' is greater. Communication systems are only one means of providing such a safety net, but as we have seen, in the twenty first century they are frequently the cheapest and most obvious to service providers. Having already examined the importance of the telephone in this respect, a more recent technological innovation in satisfying disabled people's need for security and the avoidance of harm will now be considered.

'HELP! I NEED SOMEBODY': COMMUNITY ALARMS

Under the heading *Machines to help the elderly and crippled to lead a normal life*, a 1970s futurology text claims that engineers could soon develop 'communications systems so that neighbours or relatives could be summoned if a person living alone had an accident' (Thring 1973: 116). Most of Meredith Thring's predictions remain in the realm of science-fiction. This one however has become a reality. Whilst the telephone is often used to satisfy the basic need for 'physical survival' in the event of an emergency, some research participants also had access to community alarms which serve a similar, if more limited purpose, and overcome some of the limitations of the standard telephone. These systems include speech amplification, pull cords around the home and a portable trigger (often in the form of a pendant), so calls can be made without having to get to a telephone. Calls are answered by staff at a response centre who then arrange home visits as necessary (Thornton 1993).

The first primitive system of this kind was installed in a sheltered housing scheme in 1948 (Batten 2000), and for many years alarm systems were provided only within such housing complexes as 'a "poor second" to warden coverage' (Tinker 1984: 11). There are currently around 300 of these community alarm services run by local authorities in the UK, which provide the service to those living outside these ghettos (Rica 1997). Such services are also provided by charities, housing associations, and commercial firms. The avoidance of institutionalisation is a common theme in relation to community alarms (Lindstrom and Martin 1995). Hence Leeds City Council Department of Housing Services (1998: 2-3) describe their scheme as 'a sensible caring and effective service for people who wish to remain in their own homes in the community... helping older, disabled and vulnerable people attain a higher level of care, security and independence within their own homes'.

All schemes have the same limited aim - to provide assistance in an emergency. What constitutes such an emergency however, is defined not by the users, but by the manufacturers and providers of the service. As Patricia Thornton (1993: 342) suggests:

Two assumptions dominate: potential users are older people living alone 'at risk' of injury, accident or sudden medical emergencies; and the role of technology is to assuage their 'fear' of such events and to protect them against life threatening consequences. The themes of fear, vulnerability and risk pervade promotional material directed by both manufacturers and providers at potential users.

Potential users of council run schemes are not in a position to define their own level of risk, and are subject to a 'professional' risk assessment. The local scheme for example restricts entrance to older people, those living alone, those with more severe impairments, and those who are at serious risk of abuse or harassment.

Danielle tried to join the local scheme after having intruders in her house, but did not meet their stringent criteria:

Danielle

I asked me OT if I could have one of these like alarms and he says I don't qualify for one. I'm not disabled enough. I really wanted one. 'Cos I thought, well it's something that goes straight to the police or to alert someone that summat's wrong... so they can get round soon as possible. They only give them to old people, that was the quote, only give 'em to old people or very severe disabled people.

It seems that Danielle's idea of what might constitute an emergency was different to that of the service provider. The typical priority of service providers is 'to provide a rapid response to physical injuries, often associated with falls, and to health emergencies where medically qualified attention is needed urgently' (Thornton 1993: 341). A break-in then, would not represent an emergency. It is this 'narrow and restrictive set of rules' about the acceptable usage of community alarms which limits their potential benefits to users (Thornton 1993: 340). This kind of technology could play a far wider role in allowing disabled people to define and satisfy their own support needs, perhaps enabling assistance to be summoned for activities such as bathing, or going to the shops.

Zola (1982: 395) bemoans the fact that a key concern in the design of devices for disabled people is safety: 'the protection of the individual from unnecessary harm'. He suggests that '(w)hile the wish to protect vulnerable people from danger is a worthy

goal, it is often achieved at too great a cost... There is human dignity in risk. There can be dehumanising indignity in safety'. This sentiment is shared by fellow American Gerben DeJong (1983: 247), who claims that 'the dignity of risk is what the movement for independent living is all about'. In the UK too, disabled people have demanded 'the right to take risks' (Brisenden 1998: 26). Barnes (1990) highlights the restrictive parental over-protectiveness endured by many disabled younger adults. This infantilization continues into adulthood through well-meaning risk-avoidance initiatives, and was something I encountered during the fieldwork. On a visit to John's home for example, I had to wait for over 30 minutes before I could be let in by his mother when she returned from work. Although John was in the house and was expecting me, he told me apologetically that his mother had instructed him never to answer the door unless there was someone else at home.

Current technological developments offer huge potential for increased risk management and surveillance in the future (Lyon 2001), not just for disabled people, but for other 'dependent' populations and indeed, for society as a whole. As Mark Priestley (2000: 432) suggests, disabled and older people 'have been infantilised by the development of social policies that rely on differential mechanisms of discipline and surveillance to maintain artificial states of dependency'. This infantilization has become naturalised, so that practices seen as appropriate to the care of children are unquestioningly transferred to other groups deemed 'dependent' (Hockey and James 1993). To service providers who do not want the negative publicity that an unnecessary accidental death might prompt, the opportunity for further surveillance of disabled people may seem very attractive. It seems likely then that this aspect of community alarm systems will attract the lion's share of research and development money. Writers like Maria Evandrou (1998: 281) report that trials are already being conducted of systems 'where sensors within an older person's home, locally processed via a neural network, can help to identify unusual behaviour, such as the elderly person becoming unconscious or having a fall'. There is the potential then for yet more disabling surveillance and *over-protection* in the future, as service providers attempt to decrease costs and cut staffing levels.

However, despite the fact that these technologies have been said to primarily serve the needs of manufacturers and service providers, those who were part of such schemes, were often very positive about their benefits. Patrick for example describes his care line as a 'Godsend', which enables him to continue living in the community. He has had occasion to use it on more than one occasion, and told me,

Patrick

You've got peace of mind. You feel safe... If I didn't have one, I wouldn't. Yeah, you feel more safe. You know you can get help there if you need it. It gives you more peace of mind.

Dot too was full of praise:

Dot

I just rang through once because I were on me own and I were 'aving an epileptic fit and I didn't know. I'm a bit frightened of being on me own so I just... pushed. Well they knew when I pushed and I didn't answer, to talk to me. Because they'd know I were 'aving a fit you know. So they just talked to me, just reassured me that I were all right and that they were looking after me. And that were it. Only once I've used it... they rang me daughter and she came... it's brilliant!

Even those who had not had occasion to use their alarm seemed to benefit from its presence. Take Esther for instance:

Esther/fgl

Well, touchwood - I'm touching my head - I've never had to use it since I got it. But a friend of mine fell, and they were laying on the floor for an hour because they couldn't get up to use it. Now if I fall, I can't get up ... someone's got to get me up or roll me over, you know. You see I can't get onto my knees to pull myself up, so I got one of these. Now as I say, I've never had to use it. But it is there if I need it.

It was obvious however that for some, their own needs were secondary to those of their families and 'carers'. Neil for example told me that he wanted a community alarm so that his parents could go out and leave him without worrying about him having a seizure during their absence.

Non-compliance with the rules set out by service providers is commonplace, especially amongst older people (Thornton 1993). Hence certain people were reluctant to wear the pendants which functioned as portable triggers. Dot for example told me guiltily: 'I don't wear it! I should do I know'. Maude was particularly concerned about the safety aspect of wearing hers:

Maude

They want you to wear it round your neck, but I look at it this way - you can fall, and in your fall that could slip round back of your neck and you can actually choke yourself when you're moving about. So that's why I never wear it. But you can take it with you into your bedroom or anything else where it's handy for you to pick up... But I wouldn't wear it round my neck. I mean, who knows how you're going to fall! If you fall on your front and you roll over on to your back anything can happen.

There are further problems with the hardware. Curtis highlighted how the local scheme is unsuitable for those with speech impairments. He does not have an alarm system although he lives alone, and explained that: 'It wouldn't be any good... because if they rang me they wouldn't know what I was on about'.

Other problems reported with the local scheme did not concern the hardware. Hugh for example has a security alarm system in his new bungalow, but is reluctant to use it. He is chiefly concerned about yet more strangers entering his home:

Hugh

I'm not even sure what it might do... You don't know who's coming... I wouldn't use it... because you don't know what will happen. If you know people, you're all right. If you don't know 'em you're not sure are you?

Participants in fg1 were also critical of the way that calls are dealt with by the response centre:

Frank

The thing with that - when you ring [the response centre], [they] don't send somebody to you. They get in touch with your next of kin. It's all problems all the way round. It i'n't as easy [as it's made out to be].

Esther

Yeah but what they do say, if you need a doctor or an ambulance they will call that for you and then contact your [next of kin].

Maureen

They haven't done! 18 month ago... they should 'ave rung straight for an ambulance for my mother-in-law instead of messing around with next-door-neighbour, and then them 'aving a go at me on the phone. I couldn't get across 'cos my hubby happened to have gone out. And I got [a] phone call - it'd be about tea-time - and they said they'd been trying to get hold of me all afternoon. And I said, 'you haven't been trying to get hold of me all afternoon' I said, 'cos we've been at her house!' I said 'we've only been home an hour and a half!' And in that hour and a half from us leaving her, and coming to our home to have our tea, she'd rung [the response centre].... And when we got down there she needed an ambulance. Why didn't they ring for an ambulance? ... The one that were fit enough to be able to 'ave gone across to my mother-in-law's at the time, was me daughter. And she asked social services if they'd put her a phone in so that she could be contacted, because she'd be able to get across. She lives that bit nearer - no problem or anything for her to go - and they turned her down... Well to me - she lives on her own... with my grandson like - to me that would 'ave been ideal. It would have been a lot better than it were for me and [my husband] trying to race down. 'Cos they knew we were both disabled - knew that I were like this and [he]... had his problems. So - it isn't straightforward.

(fg1)

Whilst these systems will undoubtedly ease community care expenditure, especially if made accessible to all, concerns have been voiced that far from enhancing independence for the users, such schemes could lead to further isolation. They may for example 'provide a pretext for service providers to dispense with the regular visit and the personal relationship and support offered by the sheltered housing warden' (Harding 1997: 29). It is suggested that technology 'should never be allowed to displace willing personal care' (Wolff 1986: 8) and that the 'absence of personal care should not be used as a justification for the use of a machine' (McMurray 1987: 148). The needs of the users must become paramount, or their autonomy will be undermined yet further. These concerns are also relevant when considering developments in smart housing: automated systems which purportedly increase the autonomy and 'independence' of the user. Their use-value will be discussed below.

'COMPUTER - LIGHTS!': SMART HOUSING

Martyn

Believe me, computers and communications has a lot more to offer than just talking to someone on a screen, things like that. You can actually talk to a computer to dial a number on your phone. You can tell a computer to open a door; you can tell a computer to get you a drink of water... this is the way that computers are going for disabled people.

Kathleen

Like Hugh's got his own computerised [system] to draw his curtains and put his lights on and his stereo. I think that's brilliant especially for people that are more disabled than myself. I think for some disabled people it's going to make 'em far more independent than they've ever been in their lives - unbelievable. These computerised

houses that do everything for them - you know even to making some coffee - for the disabled person I think it'd be wonderful and it should have happened years ago.

The area of smart housing conjures up images of Star Trek style technologies - the future writ large. Neither Martyn nor Kathleen had access to such a system, yet their excitement about the future possibilities is obvious. Finkelstein (1980: 11) is equally excited by the prospect of new technology which 'enables the most severely physically impaired people to operate environmental controls which can enable them to live relatively independently in the community'. What then is 'smart housing'? A typical answer might be: 'A home which can include the technology to allow for devices and systems to be controlled automatically' (Allen *et al.* 1995: 158). Others prefer to talk about 'adaptable smart housing', complaining that the usual description has an overly technical emphasis which precludes consideration of the needs of those who live in such a home. This is particularly important, as these needs may vary over time (Richardson and Poulson 1993: 87).

Both Hugh and Curtis live alone in homes fitted with 'Possums'. Possum Controls claim to have invented environmental control products over 35 years ago (Possum 1997). The systems they produce allow disabled people to operate micro-switches using a variety of input methods - for example breath control, or foot pedals. This enables them to operate various electrical appliances to control their environment, including computer interface equipment. Hugh uses a foot pedal to operate his Possum, and has been waiting in vain for it to be connected to his COL computer, so that he can operate it independently of others. He had had his computer for two years when I interviewed him, but told me:

Hugh

[I] haven't used it all that much... Haven't got a pedal. I can type with my pedal... And [the City-on-Line project manager] can't come and do it... Possum people... were gonna put a mouse on... t' Possum, so I can move the mouse around. And I'm still waiting for them to come.

Since the project is now officially over, it seems unlikely that this will ever happen.

Curtis has been living alone since his father died - 'Five years by myself. I would not go in a home'. He agreed that living alone would not be as possible without his Possum control system, and that it was 'definitely' a necessity for him, enabling him to make and receive phone calls, control lights and curtains, and operate the television and the hi-fi. As Simon Richardson and David Poulson (1993: 92) propose, such technology 'clearly offers the potential to increase individual autonomy and would indeed allow users to stay in their own home longer with an improved quality of life'. Improved quality of life in this context is too often taken to mean a decreased reliance on home care, despite the inevitable loss of human contact that such automation will create.

Whilst both Hugh and Curtis were very happy with their Possum control systems, in the long term such equipment will inevitably lead to the withdrawal of other forms of support. Cost will be a major consideration in this process. There seems to be agreement that such technology has the potential to reduce the financial burden incurred by 'care' providers as the population ages yet further (Richard and Poulson 1993). Recent research however, whilst proclaiming the benefits of such technology for 'the elderly, infirm and disabled' who might otherwise be 'totally reliant on home care', suggests that those aged 55 or over showed the least interest in living in a Smart Home, and were the most concerned about potential technical problems (Pragnell *et al.* 2000: v). Maude had evidently seen the 1977 science-fiction movie *Demon Seed*, and was certainly concerned about the potential for technical difficulties:

Maude

All these books that were written on sci-fi - it's actually coming true today isn't it? And I saw this film and it were computers. And a computer and it was a massive thing, and it actually took over everything. This one big huge machine and it could control all other computers around it and way beyond. And actually it took a person's life over and dictated to 'em. It took prisoners and wouldn't let them go because the computer took a liking to the woman. And I thought: 'Ugh, God!'. But who knows?...

It can be frightening I think, the world today what they're dreaming up. I think it can be very frightening actually.

At present it is 'the avant-garde high-value end of the property market' that is creating the impetus for the development of Smart Home technology (Pragnell *et al.* 2000: 20). It is suggested though that a mass consumer market could soon develop, driving down costs and thus increasing availability (Gill 1996; Pragnell *et al.* 2000). Malcolm Harrison (2001) is doubtful about the usefulness of this market led, 'trickle-down' approach to the diffusion of Smart Home technology, and suggests that public sector agencies should become more involved, consulting with potential user groups to develop solutions which will reduce barriers to independent living.

It is suggested that the idea of the smart home is both exciting and challenging, and that: 'Much like the introduction of television, you may love it or hate it; but either way it is here to stay' (Allen *et al.* 1995: 17). We cannot however afford to accept the technological determinist argument that this technology is 'here to stay'. Too much is at stake. If the technology is provided merely as a cost cutting exercise, many disabled people could find themselves confined in, and dependent on an automated home. Technology alone cannot be relied upon 'to solve care problems' (Richardson and Poulson 1993: 92). Human support is also necessary. Furthermore, such technology must be developed in accordance with the self-identified needs of the users, not 'solely on the basis of technological feasibility' (Richardson and Poulson 1993: 94). Some doubt that this will ever happen however, proposing that the needs of disabled people 'will not, in themselves, greatly effect the design of new technologies - much as many would like to think they will' (Allen *et al.* 1995: 171). The concept of smart houses *is* exciting. If disabled people are allowed to determine its future direction, the reality could be even more exciting.

Amidst all this excitement, it is important to remember that many disabled people, including those involved in the fieldwork, cannot get funding for even relatively minor household adaptations. Vera, for example, a Colliers Resource Centre user, waited for over three years to have an accessible shower fitted by the council. Patrick

was unable to use his own kitchen. The situation may well be no different for those who might benefit from 'smart housing' in the future.

SECURITY AND AUTONOMY OUTSIDE THE HOME

The fieldwork demonstrated then, that there are various ways in which communication systems are used in the home to satisfy disabled people's basic needs for physical survival and autonomy. Without similar systems which can be used outside the home, disabled people may be reluctant to venture out at all. This section will discuss the ways in which the fieldwork participants used (or were often unable to use) communication systems to satisfy their need for security and autonomy outside the home. Specifically, it will consider 'public' and mobile telephones.

'Public' telephones: A public disgrace

Neil

A lot of telephone boxes you get outside you can't get into anyway in a wheelchair... They're not useable by disabled people.

Patrick

I can't get in [a] telephone box... Well I wouldn't be able to use one 'cos I won't be able to reach.

Whilst many public payphones are now sited in kiosks built to a more modern and accessible design than the traditional red phone box (BT 1999), many of the participants were still concerned about access. As with public transport, it seems that disabled people are not considered to be part of the general public. The fact that *some* kiosks are now accessible does little to put disabled people's minds at rest. Whilst the above points were raised by wheelchair users, access issues were also raised in

relation to other kinds of impairment, for example, impairments affecting dexterity and vision:

Neil/fg2

You know, a telephone where you have to dial the number, you have to hold the hand set and... put the money in... You need two hands really and I've only got one hand like... By the time they say 'hello' and you get to put the money in, I answer and they've just put the phone down. It's awkward.

Max

You know the ones where you have to push a button when you get through? I don't think they're always in the same place the buttons. They're quite difficult. I've never used a telephone card one. I know some people that're blind do use them, so you obviously can use them. But then of course you wouldn't be able to see what you've got left on your card. It comes on the display doesn't it?

Because of the continuing inaccessibility of pay phones, several participants commented that they needed a mobile phone in case of emergencies whilst they were outside the home. As Neil told me:

Neil

I think for the outside, you need a mobile phone. If you're outside you can't get in the phone box... with a mobile phone it's there, you know with you all the time... I tell you a mobile phone would make a big difference.

Helen, who has a visual impairment, shares the use of a mobile phone with her jobshare partner, who uses a wheelchair. As she explained, a mobile phone is necessary for both of them:

Helen

For my jobshare partner, public phones are an access issue 'cos of the height and that. For me, a public phone's an access issue because I can't find them! [laughter]

Even when access is not a problem, the scarcity of public telephones may cause anxiety (Drake 1999). This is unlikely to improve, since BT has now announced that they will no longer make phone boxes: 'they are not profitable in an age when the mobile phone is the undisputed king' (Dyckhoff 2001: 8). The cost of making a call from a phone box has also doubled, as the growing use of mobile phones makes phone boxes 'less viable'. This move will inevitably 'marginalise thousands of people who do not have access to a phone at home or a mobile' (Morris 2000: 1). It is likely that the provision of public telephones will deteriorate yet further as we take 'one more goose step towards shiny netted-up New Britain, where, some day soon, mobile phones will become compulsory for all' (Dyckhoff 2001: 8). A radical monopoly is thus being created, as the mobile phone becomes a basic necessity. This does not augur well for those with limited resources.

As disabled people are so poorly served by so called 'public' telephones, the fieldwork demonstrated that there was a great deal of interest in mobile devices for use outside the home. Barriers exist however to prevent their beneficial use. This newly emerging radical monopoly will now be considered:

Mobile phones: Benefits

Bill

They're saying 'right that's it, you can do your shopping from your 'ouse'... It'd be more important if they said 'right, go outside, live your life, here's a mobile phone, and get a discount off it'. It'd give people more independence, more reason to live... 'Cos you can go out where you want, when you want. You don't need to worry about if your mate's gonna be there to phone you up a taxi. There's no need [to] worry about can I go in a phone box, will I have to ask someone to dial the number for me, can I

trust someone to dial a phone number?... And say like if your wheelchair conks out, your electric wheelchair, you can't move because there's no way you can free wheel an electric one. So you're stuck there. So you could phone someone up from where you're actually sat. Not only that - if say like you're in a car and you're a woman travelling alone or a disabled person, and say like if you're stuck on a motorway or wherever or get a flat tyre on t' side of the road - phone someone up, get someone to come out and see to it. Or if you're ever in trouble, same way as an electric wheelchair. I mean you 'ear about muggings and Lord knows what... And sort of like, it's that independence. It gives you a reason, a life worth living!

Whereas home based communication systems such as PCs were sometimes thought to provide another means of segregating disabled people in their houses, mobile devices were often seen as an important tool enabling participation in a sometimes hostile outside world.

The perception of crime and violence on the streets makes many older people afraid to leave their homes (Drake 1999; Harding 1997), despite the fact that they are no more likely to be targeted than those who are younger (Brearley *et al.* 1982; Help the Aged 1999). The consequences of crime may be more serious for older people however, as they are 'more frail and are therefore especially harmed by violence, and because they have lower incomes and therefore incur relatively greater economic costs' (Brearley *et al.* 1982: 43). Furthermore, as Help the Aged (1999: 2) state, 'The fact that we are unlikely to be victims of crime does not stop us from worrying about what might happen'. The same holds true for disabled people. As Bill told me, 'you daredn't go out of your 'ouse'. Those research participants who had managed to afford mobile phones were motivated primarily by worries about 'what might happen', not just in terms of crime, but also in terms of getting lost, wheelchair malfunction, or car break-down.

Whilst mobile phone ownership in the UK has risen to at least four in ten people (Teather 2000), Kathleen was one of only four interview participants who reported having the use of a mobile phone. Another two had acquired mobile phones, but were unable to keep up with the necessary payments to keep them running. Fg3

participants Norris and Caroline also had the use of a mobile phone. Kathleen was prompted to buy hers after a frightening incident driving home one night. Helen's motivation for securing the use of a mobile phone in her job, was the fear of losing her bearings:

Kathleen

It's cost me 'undred and twenty five pound for the year, but it's for me own security. 'Cos I do go out and about, and I go on motorways and that. If I get on a motorway, I can't walk to a phone. You haven't to open your door to anybody passing, so you know, what do you do! So that's why I got a mobile phone. Not to be a yuppie, just for me own piece of mind.

Helen

When I got this job, I sort of said, 'well, what about a mobile phone?' I don't like them, but I think, like say for instance if I was going out to... somewhere that I wasn't familiar with, then at least I would have the means to sort of ring a taxi or ring work and say 'look, I'm on this street. It looks like this. I haven't got the foggiest idea where I am! Come and find me!'

Others highlighted the importance of mobile communications in the event of 'a "dead-lock" situation' (Freitas *et al.* 1995: 139) - the breakdown of a mobility aid like an electric wheelchair or a car:

Bill

I'm in here in an electric wheelchair... They break down... And you go out, what 'appens if you break down? You can't get to a phone box... you couldn't break down and then get carried to a phone box - you know what I mean? And nine out of ten aren't accessible anyway, phone boxes. And you feel right cheeky saying to someone 'Hi, I've broken down. Can you give us a shove to a phone box?' [laughter] 'Oh I can't make a phone call!' So I mean a mobile phone seems obvious.

Kathleen

I wanted one 'cos I drive. I know all about cars, but literally if I have a puncture I cannot do anything about it, 'cos I just can't jack me own car up!

Even those like Frank, who were on the whole uninterested in modern 'gimmicks' could recognise the use-value of mobile phones in the event of car trouble.

Bill described his satisfaction at being able to call for assistance himself when he was able to afford a mobile phone:

Bill

I mean I conked out in the middle of the road up at t' top, and I mean there were no laughing about it, there were nowt I could do... I 'ad to phone 'ome... then our kid came up and got me. He got me chair going... But it were nice that I could do that. I mean someone pushed me off o' t' road and that's all there were to do - left me at side o' t' road, asked me if I wanted any more 'elp. But it's when you 'ave to do stuff like that. I mean, you feel really cheeky. You know what I mean? I know you've got to get on and live your life, but... it doesn't make you feel good about yourself. I think what made me feel good were that I did 'ave a mobile phone at the time... if I hadn't of had a mobile phone, I'd of 'ad to ask someone to go to a phone, take me to a phone box. And not only that but [ask] if they'll phone our 'ouse up. And, I don't know, the feeling!

Unfortunately, his pay-as-you-go system proved too expensive to be maintained, and is now in a drawer at home out of credit. As he explained: 'you'd already paid for your phone calls, which was good, because I didn't have to pay these whacking bills. But it were really expensive'. Danielle is no longer using her mobile phone because of the expense, but does not feel that a mobile phone is a top priority for her:

Danielle

There's other things that I want. It's not a must if you see what I mean, 'cos I've got my pager and if I go anywhere, I don't usually go by myself. I'm usually with some friends. So if anything does 'appen to me somebody's there to always help out.

Whilst other participants agreed with Danielle that a mobile phone was not something they needed or wanted, several felt that such a system would be of great use to them. Various access issues were raised however which prevented this beneficial use. While access issues have been covered in previous chapters, it is difficult to discuss mobile telephony without some mention of access. The salient points will be briefly discussed below.

Mobile phones: Barriers

Neil/fgl

It's just the expense for a disabled person really... Even though I need one, and it's very useful if you 'ave one. It's just the cost for people, you know on disabled benefits. [I've] no way of buying one or getting one.

Despite the enthusiasm demonstrated in the fieldwork for mobile communication systems, there are as yet no schemes through which such equipment can be funded. Although prices are coming down, they still represent a substantial barrier for many disabled people (Freitas *et al.* 1995). Whilst there is an increasing amount of attention given to the provision of computer equipment for disabled people, mobile phones seem a low priority. This was a source of some consternation for Bill: 'I mean how much does a computer cost? How many mobile phones could you buy with that?'. Andrew also suggested that people who have difficulties in using public telephones should be provided with mobile phones in case of emergency:

Andrew

If they're going out anywhere and the wheelchair breaks down - if they didn't have a mobile phone, how would they get to the telephone? So I think they should 'ave a mobile phone... all people who's in a chair... Disabled people such as myself who can walk an' that, it's fair enough... I think people that can get to telephones - I don't think they should 'ave mobile phone, unless they're going to pay for one out of their own money. But I think mobile phone's mainly for t' elderly and disabled - mainly for anybody really. But me personally, I would 'ave 'em for t' disabled... It gives 'em more independence.

It seems then that we are still a long way from seeing this 'vision of the future': 'to provide by the early 2000s to everyone who needs it, the access to a pocket-sized personal communicator' (Freitas *et al.* 1995: 137). This cannot happen without some form of external funding. Section 2 of the CSDPA could usefully be reformulated to accommodate the changing telecommunications environment, or as mentioned previously, DLA could incorporate such extra costs.

Lack of information presents another barrier to mobile phone use, with many people confused by the vast array of models and contracts offered. Mobile phones are notoriously difficult to choose, and this process becomes yet more difficult if you have an impairment. Max for example recognises the use-value of mobile phones for himself and his partner, but seems bewildered by the prospect of selecting one:

Max

Yeah, we've thought about it. But there's so many different [ones]...and we'd only like use it in emergencies I think, and a lot of them you've got to spend so much a month haven't you? And there's a lot of different ones i'n't there? And I think we would get one. We will get one probably eventually... I think they would be handy for people like us really.

Mobile telephony presents particular access difficulties for those with certain impairments - visual impairments being an obvious example (Freitas *et al.* 1995) -

and information about appropriate models is not readily available. Whilst companies like BT are beginning to consider their disabled customers, the growing number of mobile phone manufacturers do not appear to have made this a priority (see Chapter Four). Tony Shipley and John Gill (2000: 10) hypothesise that:

The mobile phone business is characterised by high sales volumes and low prices with short product life-spans. Dedicated products aimed at specific parts of the community tend to be made in low volumes, at high prices, and with long periods between design updates. This does not make them attractive for manufacturer or consumer.

They further surmise that accessibility cannot be considered with new technologies like mobile telephones, or innovation would be stifled. With 'innovation' counterpoised against 'access', the only current option for many disabled people is to make do with inappropriate 'mainstream' models. As Max and Helen told me, this is far from satisfactory:

Max

A lot of them seem quite fiddly... A lot of them are very small aren't they? And a lot of them have a lot of stuff on don't they like message takers, all that sort of stuff? We just want a complete basic. That's all we'd want really.

Helen/fg3

I've got the three numbers that I need programmed into it to cover for emergencies. If I try and dial anything else [I'm in trouble]. The numbers aren't very big.

All of the systems described above are being constantly modified and 'improved'. Indeed, many developments such as the new Internet ready WAP (Wireless Application Protocol) phones have only become available since the fieldwork was conducted. Even WAP phones are set to be superseded by 'third generation', UMTS (Universal Mobile Telecommunications System) phones. Whether this will represent progress for disabled people remains to be seen. It may open up yet more opportunity for disabling surveillance. Even now, a mobile phone constantly gives an indication

of your approximate position, and the third generation will increase accuracy to within tens of metres, using satellite assisted global positioning system (GPS) technology (Mathieson 2001).

Many of the research participants found it difficult to imagine the technologies that they would like to see developed in the future. Martyn however had the following suggestion:

Martyn

Now if I'm outside, away from the technology of the 21st century, and I fall out of my wheelchair, I need help. So I'd like a nice little watch that says 'help'. It relays to the computer, the computer sends the message out and I get help. I know it's far fetched, but ...that's what I'd like to see.

Third generation mobile phones may allow just such a system, with help being summoned via the Internet (Batten 2000). However, physical accessibility must be rigorously enforced, and appropriate funding made available, if *all* disabled people are to benefit and not just an elite minority.

SUMMARY

Just like the population as a whole, disabled individuals need to avoid harm, feel secure, and have choice and control in their lives. Unlike the population as a whole, these needs are seldom met. Whilst communication systems have great potential as satisfiers of these needs, they must not be seen as the only possible satisfier. They are increasingly provided as a short-term solution to the larger social problems of inequality, isolation and increasing lack of resources in the welfare state. Hence in the future, disabled people may still be forced into positions of dependency - not on professional service providers as previously, but on the machines which have taken over these jobs. Their own self-defined needs must be prioritised in any future

planning around human welfare and technology. Far from increasing their autonomy, systems which are designed and provided without the input of the eventual users may decrease disabled people's capacity for choice yet further. As Ruth Hubbard (1997: 200) suggests of reproductive technology:

Until mechanisms exist that give people a decisive voice in setting the relevant scientific and technical agendas and until scientists and physicians are made accountable to the people whose lives they change, technical innovations do not constitute new choices. They merely replace existing social constraints with new ones.

Questions of access still loom large, and the fieldwork strongly supports the case for widening the scope of state funding to include for example mobile devices.

As yet, the use value of the Internet has received little attention, since at present, its usefulness is limited in an emergency situation. The increasing popularity of this technology has massive implications however for the way that information and other commodities may be provided in the future. At present, disabled people have limited access to such goods. The following chapter will examine whether technology has the potential to improve this situation.

CHAPTER SEVEN: INFORMATION, CITIZENSHIP AND CONSUMPTION

This chapter will further consider the possibilities for increased autonomy offered through disabled people's use of communication systems. In particular, the use-value of such systems in the consumption of commodities will be examined. The Internet is increasingly becoming an electronic marketplace, where anything from books to babies can be purchased, and information is one of the key commodities on offer. Modern living in the West is now almost impossible without consumption, hence the consumption of both material goods and information is frequently linked with citizenship. Disabled people who are denied the opportunities to access the world of consumption in traditional ways may find these citizenship rights are honoured through the utilisation of ICTs. Alternatively, this may represent the ultimate technical fix, as the High Street as we know it closes for business, and accessing information without a computer becomes an impossibility. As the COL project had facilities for both shopping and information provision, this chapter will draw heavily on the experiences of COL participants.

SHOPPING AROUND FOR INFORMATION

Information, loosely defined as 'any unit of data or knowledge' (Jary and Jary 1995: 322), has growing primacy in today's world. Access to information is thought crucial in making decisions and exercising autonomy, and is increasingly regarded as an important right of citizenship. As discussed in Chapter Four, there is a paucity of information available about accessible communication systems. The story is the same for other areas of our lives. Disabled people have traditionally been subject to 'information disability', a specific form of social oppression created by 'the way in our society we present, or withhold, information and prevent opportunity for participation

in the mainstream of social life' (Davis and Woodward 1983: 329). Communication systems have the potential to provide new ways for disabled people to obtain the information they need, in formats which are accessible to them. At the same time however, information is increasingly described as a commodity akin to the 'vast range of other commodities whose existence... depends on common capitalist relations of production' (Schiller 1997: 109). Information then has an exchange value, and intellectual copyright is jealously guarded.

The idea of copyright was born alongside the invention of the printing press (McLuhan and Fiore 1967). However, its protection has now reached unprecedented levels through the efforts of international organisations such as WIPO (the World Intellectual Property Organization), one of the leading United Nations (UN) organisations. Information's 'expanding and intensifying exploitation as a capital good' (Schiller 1997: 113) is evident in current, high-profile struggles 'between western patent rights and the rest of the world's need for affordable medicine' (Borger 2001: 14), in attempts to profit from the human genome, and in the curbing by record companies of Napster's file-sharing powers. This commodification has wide implications, and may create particular problems for already disadvantaged groups such as disabled people who usually 'do not have sufficient spare cash to use to buy the information and advice they need' (Moore *et al.* 1994: 29). Since there is 'no such thing as free information, even if information is provided free at the point of delivery' (Hinkley and Steele 1992: 8), continued state funding of disability information services remains paramount (Moore *et al.* 1994). Whether this funding will continue for long in the twenty first century is a matter of concern however.

We are now said to be living in a 'consumer society' (Bauman 1998b; Edwards 2000; Illich 1973) and citizenship rights are increasingly equated with consumer rights - for example in the definition contained in the Citizen's Charter (Murdoch 1999). In the area of consumption too, ICTs may offer new forms of access for disabled people. As ever though, these developments could present new barriers (Sheldon 1998b). Hence, this chapter will conclude with a consideration of the accessibility of the information and services offered through the Internet, and the case for regulation of the World Wide Web will be examined.

Information retrieval and shopping are, according to Bill Gates (1996: 75), two of the things that 'will in time become killer applications for the Internet'. Whilst various services like banking, are now offered via the telecommunications network, the discussion below will focus predominantly on the potential for remote shopping. Disabled people can face extreme difficulties in purchasing consumer goods, not just because of their financial position, but also because of factors such as transport disability and lack of access to the built environment. As Tim Edwards (2000: 30) contends, consumption patterns in western society are socially determined so that 'the elderly and infirm, and the low paid in particular, are excluded from many consumption practices through various mechanisms from transport to credit control'.

Because of the many barriers placed in their way, disabled people are often dependent on others to take them shopping, or to shop on their behalf. As will be examined below, online or teleshopping is often hailed as a new means for disabled people to access the world of mass consumption without the need for assistance. Disabled people are not generally in a position to indulge in 'conspicuous consumption', an activity of the affluent 'leisure class' (Veblen 1934). However, in today's society making do without consumption has become impossible: 'how does one partake in Western society or even survive without consuming its products?' (Edwards 2000: 12-13). Since satisfying even the most basic need for food entails the purchase of commodities, the discussion will focus primarily on those aspects of consumption which are 'mundane and routine matters of necessity' (Edwards 2000: 4). The COL project had a supermarket partner enabling the remote purchase of groceries, and the experiences and opinions of those on the project regarding online shopping are a refreshing palliative to the usual 'expert' pronouncements. The views of disabled people have so far been conspicuously absent in this area, and this chapter will begin to rectify this imbalance. First though, information and its importance in citizenship will be considered.

INFORMATION AND CITIZENSHIP

Open information is the raw material of knowledge. Knowledge is the basic tool needed to participate effectively in any activity or social organisation... In the absence of open information disabled people cannot effectively participate in their society. (Davis and Woodward 1983: 328)

The late twentieth century saw the 'reintroduction of the idea of citizenship' - a way of conceptualising 'the relationship between the individual and the State at times when this relationship is in crisis' (Oliver 1996a: 145), and '*a popular slogan of governments who espouse a commitment to democratic ideals*' (Barton 1993: 235). Citizens are said to be entitled to certain rights - civil, political, and social and economic (Marshall 1950). In return, it is expected that certain responsibilities be shouldered - hence, the current 'third way' mantra that 'individuals owe a duty to one another and to a broader society' (Blair 1994: 4).

'Access to information and citizenship are very closely related' (Christie and Mensah-Coker 1999: 61), and in recent years various authors have extended Marshall's schema of three sets of citizen rights to include a fourth dimension - informational rights (Christie and Mensah-Coker 1999; Hasler 1993b; Murdoch 1999). Whilst access to information is considered vital for *all* in today's society, it is a particular concern for disabled people and their organisations. Information is identified as the first of the seven needs of disabled people (Davis and Mullender 1993). It is a need that arises 'in a context of unequal power, of institutionalised discrimination' (Hasler 1993b: 11) and hence is a need that all too often remains unsatisfied. As Linda Marsh (1994: 1) suggests the need for open access to information is especially important for disabled people because 'they are often isolated within society by other barriers, such as physical access to buildings, transport, education, employment'.

Because of these barriers, disabled people often require 'specialist information in addition to that needed by everybody else' (Oliver and Barnes 1998: 81). Whilst there is a vast body of specialist, 'disability information' available however, little of it gets to those 'isolated disabled individuals' who need it the most (Hasler 1993b: 12). Furthermore, there is a lack of clarity over what actually constitutes 'disability

information' (Findlay 1994; Hasler 1993b). Most of the information services funded to provide so called disability information are controlled by non-disabled people who subscribe to the medical rather than the social model of disability, with vast amounts of public money being given by central government to charities and voluntary organisations (Hinkley and Steele 1992). As Bob Findlay (1994: 1) explains

disability information has come to represent a patronising attempt to help disabled people overcome their problems - the problems caused by having impairments and not being able to access information because of those impairments. And of course, their needs and interest are *special*.

Whilst there is of course a place for impairment information, especially at 'crisis points' such as receipt of a medical diagnosis (Scott 1993: 31), according to Findlay (1994: 1), disability information should first and foremost address the unmet needs of those who experience disability oppression, looking for example at 'the consequences of living in a disabling society' and facilitating those with impairments to overcome social barriers. What disabled people need to know then is 'quite literally how to live as equal citizens' (Hasler 1993b: 13).

Preferably, this information should be provided by those who experience such social oppression, since 'a type of authority which speaks particularly strongly to disabled people is one with experience of disability' (Nadash 1993: 2). As Frances Hasler (1993b: 13) contends: 'If the information we are given does not start from a disabled viewpoint it is not the information we need'. The disabled people's movement has therefore demanded that all disability information services are controlled and run by disabled people (Nadash 1993). Publications such as GMCDP's *Information Bulletin* and BCODP's *Update* are a move towards this goal, but a reallocation of public resources is necessary if these organisations are to reach those disabled people who do not request, or even know about, such sources of information. Agencies governed by non-disabled people have far greater access to resources than those controlled by disabled people (Drake 1994; Hasler 1993b), and this situation must be rectified if 'real disability information' is to be provided (Hasler 1993b: 19).

A major expense for organisations of disabled people concerns the provision of information in different accessible formats. This is not always a priority for other organisations, so those with learning difficulties, sensory impairments, and/or those whose first language is not English often face particular hurdles when accessing information. Much available information is 'full of acronyms and long words' creating particular problems for those with learning difficulties (Moffatt 1993: 30). Those with visual impairments are disabled by standard print, and seldom have their informational needs met in terms of alternative formats. British sign language (BSL), the first language of around 70, 000 Deaf people in the UK is still not recognised by the government as an official language, and the refusal of successive governments to recognise BSL has, according to a British Deaf Association (BDA) spokesperson 'caused widespread discrimination, with deaf people denied access to information and services' (Disability Now 2001: 7). The provision of information in a variety of formats would constitute a 'reasonable adjustment' for service providers to make under the DDA, and companies such as BT are making advances in this area. There is little to suggest however that this has become a widespread priority. ICTs allow a variety of output formats, and may therefore have the potential to enable access to otherwise inaccessible information. The use of the Internet to access information and promote citizenship will now be considered:

INFORMATION TECHNOLOGY AND INCLUSIVE CITIZENSHIP

Opportunities for both access to information and for effective citizenship, have arguably undergone a transformation with the increasing prominence of information and communication technologies. According to some, the new technologies could, *'if supported by suitable policies and attitudes*, play a major role in promoting equality and inclusive citizenship' (Christie and Mensah-Coker 1999: 14). Since disabled people were 'information poor' before the term was used in its currently fashionable technological sense, can we expect technology to improve this situation? There is

without doubt a growing body of information produced by and for disabled people available on the Internet, and for those with the technology, this is enabling access to hitherto undreamed of information.

The majority of disabled people are not however in a position to benefit from this wealth of information, for reasons already discussed (see Chapters Four and Five). Without substantial changes then, 'easy access to the information that can really empower and liberate people still looks likely to be the preserve of an affluent minority' (Haywood 1998: 26), since the expansion of online information services 'has not been matched by a similar growth in the availability and access to such services for historically disadvantaged social groups' (Mele 1999: 306).

Furthermore, in the current political climate, the increased use of information technology as a means of disseminating information may have a deleterious effect on other means of information provision. People interviewed by Barnes (1995: 39) predicted 'with some trepidation', that information might in the future be provided only for the computer, and others voice similar concerns:

The strongly emerging imperative that all information should be regarded as a market-driven commodity, has had a deleterious effect on current perceptions of publicly funded sources of information... The loss of cheap paper sources of information as the build-up of digitalisation accelerates is a little considered issue in the context of wide public access to sources of information. But without institutions to mediate digitised information to economically deprived groups, their access to something that was often relatively easy via a public library, law centre or citizens advice bureau could be severely impaired. (Haywood 1998: 22)

It is even possible that plentiful electronically provided information might provide a new means of victim blaming. The more that such information becomes available, the easier it is to blame individuals for their circumstances, and thus 'to blame the poor for their poverty' (Fitzpatrick 2000: 388). This could have significant implications in terms of citizenship, especially perhaps for disabled people who are already denied many of their citizenship rights.

The ways in which the disabled people who participated in the fieldwork were using the Internet to access information will now be considered:

HITCHING A RIDE ON THE INFORMATION SUPERHIGHWAY

Helen

The whole information provision thing I find really exciting, you know. Whether it's on computer or other means. I just think there's so much potential for information provision.

Neil/fg2

I think it's great - especially for disabled people - look for information and you can get it no matter where it is

There was a lot of enthusiasm for the Internet's potential in information provision. Those who used the Internet at their resource centre were particularly struck by the savings in travel, money and time that accessing information in this way could allow. It was often difficult however to pin down exactly what sort of information people were accessing, perhaps because this was something they considered private. Broadly speaking, it seemed there were two main motivations for accessing information on the Internet. As Danielle suggested:

Danielle

It's basically what I fancy at the time! [laughter] Or what I really need to find information about, you know

Much of the information being accessed then was of general interest, often relating to leisure pursuits or hobbies. The Internet was also used, although to a lesser degree, to access 'specialist information' relating to disability issues such as access to buildings and transport. These two broad areas will now be considered:

'What I fancy at the time': General information

Most of the information being sought on the Internet by the disabled people participating in the fieldwork was about leisure pursuits. Neil for example was mainly interested in finding 'general information, like what's on at t' pictures and football, fishing'. John also likes to follow sport. When I interviewed him, he was planning to use the Internet to 'get to know all the facts and figures about the World Cup'. Kate has visited 'Chin-net' to get information and advice about breeding from her children's pet chinchillas, and Curtis's favourite web-sites are about space travel. He told me it was 'like going to a library. You can get anything'. It suits him better than a library however, because he cannot hold a book. Others like Dot and Danielle often follow up web-sites which are related to favourite television programmes.

Another popular usage was to obtain information about holidays. Whilst this is essentially leisure information (Hasler 1993b), the focus was often on the accessibility of holiday locations. Several of those who were able to access the Internet at their resource centre enjoyed looking up such information for other users as well as for themselves. Some also reported doing unpaid 'finding out' for paid resource centre staff. Rather than feeling exploited by this, they seemed pleased to be of assistance:

Ray

I also do stuff for one of the outreach workers at Colliers, 'cos they've got little time themselves to do it.

Caroline

Do they pay you for it?

Ray

No - I just do it. It helps me as [well]. You know, you're teaching yourself. You know, you get familiar with these things and how you access them.

(fg3)

Surfing the net then provided a means by which computer literate disabled people could assist others. It was also another form of leisure activity for many, relieving the

boredom of the resource centre, or their enforced isolation in the home. As Curtis said of his time with an Internet connection:

Curtis

It took up a lot of my time. I don't watch telly very much. I'd rather be in the Internet finding out things.

'What I really need to find information about': Specialist Information

All the resource centres where fieldwork was conducted boasted an 'information room' containing leaflets relating to disability issues such as benefits and equipment. My impression was that this information was little utilised, something that Frank backed up. He was doubtful about the use-value of the Internet as a means of providing information for disabled people, since the resources already available to them were gathering dust.

However, some Internet users *were* going online to find specialist information. In fg3 for example, Caroline reported using the Internet to look at 'Disabilitynet - things like that' and Ray had found it useful to find historical information about disabled people's oppression:

Ray/fg3

I've been doing a lot of this euthanasia, eugenics... stuff from the thirties... It's instant access. Instead of having to look through a book you can get instant access to that specific subject. You don't have to wade through four or five hundred pages looking for a certain little bit.

It was also used to find out about access to the environment. Danielle for example had used the Internet to plan journeys out of her local area:

Danielle

I used it once when I was going down to London and I wanted to know what accessible transport London had. And I got that off the Internet. And timetables and stuff like that... So it's good for planning a journey as well.

Information about the accessibility of the *local* environment was also thought important. COL produced an online local access guide for those who were part of the project, although due to a lack of adequate training, some participants had not been able to access it. Those who had used the guide were very enthusiastic about it, describing it for example as 'the best thing on it' (Bill). Kate explained how it had been of use to her:

Kate

I needed to take my son to a concert... and I wasn't quite sure where I could park or how I could get in. I'd got a bit of an idea of it, but it sort of gave me the exact information. Also it told me a vital piece of information, that the door opened half an hour before performances... And it gave me the reassurance that there was a toilet for disabled people, which I often wonder [about]. So that was good. Yes, I've used it a few times. There needs to be more information on there.

Originally, the intention was that the access guide would be interactive, so that users could add to, or modify the information, based on their own experiences. As Kate explained, this never happened as planned:

Kate

Did you know that [it] was supposed to be this thing that we were all supposed to be involved in? I've been on to them a few times about it... they put us in touch with somebody for our area who was going to use us for our area, and I've been in touch with him a few times and he's not really getting his act together. It's somewhere within [the] City Council, but they're not quite getting their act together on it.

This was another weakness of the COL project. For disabled people to become more than passive consumers of information, they must have some control over the process of information provision. The control of information by non-disabled people is said to intimidate and disenfranchise disabled people (Scott 1992). Furthermore, as Alberto Melucci (1996: 180) suggests:

As mere consumers of information, people are excluded from the discussion on the logic that organizes this flow of information; they are there only to receive it and have no access to the power that shapes reality through the controlled ebb and flow of information.

He further contends that the lack of this kind of control constitutes a kind of exploitation for those without the power to organise information according to their needs. It follows then that we must 'become our own experts' (UPIAS 1976: 18), and take control of the information that we lack. This must include *all* aspects of the information that could help us to rectify our collective situation. We need 'hard' information - 'facts and figures', and 'soft' information - the 'subjective and experiential' information that only our peers can supply (Nadesh 1993: 2). This soft, informal information: 'is the fruit of collective experience, and it has to be constantly updated, because every new experience modifies it' (Hasler 1993b: 15). Whilst there are difficulties in publishing this kind of information, it may be the most useful to disabled people (Hasler 1993b). Pamela Nadesh (1993) also highlights the difficulties of incorporating 'soft' information into a paper directory, yet this is a vital area of information provision that often remains unfulfilled. It is here that the Internet could have great use-value, being able to incorporate not only hard/formal information, but also providing an invaluable means for disabled people to collectively collate and disseminate such informal information. Walch (1999: 145) lists twelve categories of computer support for emancipatory action, the first of which is *media substitution* - using the Internet, standard media can be circumvented and information 'de-mediated'. It is an indication of the general lack of regard for disabled people as their own experts, that those involved in the COL project did not allow participants this kind of input.

Whilst the Internet has certain potentials, the fieldwork demonstrated that disabled people still have difficulties accessing and utilising the information they need, and may find themselves suffering from 'information overload' (Jordan 1999: 101). These difficulties will be briefly considered:

Information overload? Finding the relevant information

Having too much information can make use of information impossible. This can occur in two ways. First, there can be simply too much information to absorb. Second, information can be so poorly organised that finding any particular piece of information becomes impossible. (Jordan 1999: 101)

Even if the desired information is found, it may be of little use, since information is 'pretty useless when it is just facts' (McGahan 1993: 60). As Graham Murdoch (1999: 30) suggests, to convert raw information into useful knowledge, we need a broad array of 'arguments and conceptual frames through which it can be interpreted and evaluated and its implications traced'. In order to achieve this transformation, we may need help from others. Hence a common theme in writings about disability information provision is the role of advice in enabling disabled people to use information to their advantage (Barnes 1991; Hinckley and Steele 1992; Nadash 1993). Members of the National Disability Information Project (NDIP) team (now ADAIP) for example suggest that giving information without advice 'can reduce the likelihood of the person acting on the information given' (Hinkley and Steele 1992: 10). Likewise Barnes (1991) highlights the importance of counselling help in making proper use of available information. It is often difficult to distinguish between information and advice (Nadash 1993). This may underlie the preference amongst many disabled people for information to be provided face-to-face (Scott 1993). Whilst the Internet is replete with raw information and facts, it may fare less well as an advice giver. This may create problems in distinguishing between useful and useless information:

Norris/fg3

There's so much on it i'n't there?... You know, if you want information about one thing you get a load of stuff and you've got to find were you were going. It's overwhelming sometimes.

This is a common problem for all Internet users, not just for those with impairments. As Steve Jones (1997: 25) contends one of the biggest problems with the Internet is 'the inability to organize and catalogue its contents, despite the proliferation of "search engines" for indexing Web sites and Usenet newsgroups'. For disabled users, who are often unsure what information they actually need (Gormley and Walters 1983), this uncertainty makes the time taken to find information on the Internet a major concern. Helen highlighted how some people take more time than others to access information on the Internet, thus incurring a cost penalty:

Helen/fg3

There are issues as well around how fast you can actually use the computer when you're accessing information. If for whatever reason you're actually a slow user... then it is obviously costing you more and more to access it. You know, just selecting what you want to download or whatever takes more time.

Kathleen agreed about the expense incurred whilst trying to find information:

Kathleen

I think a lot of money's wasted. It's a dear do just to be browsing, just to try and find out what you want. It's like your telephone - you ring ten numbers up just to speak to one person - it's the same principal... Just wouldn't do it would you? You'd find that number out and ring that. Well it's the same principal on your thing. You put the wrong lettering in and you go through ten things while all the time the Internet's adding up and adding up and adding up. I just can't afford to do that. I need to know a specific thing you know, a specific address - albeit one word - to be able to point me down the right track.

Such considerations may also limit the use-value of the Internet as an electronic marketplace for purchasing goods, as will now be discussed.

INCONSPICUOUS CONSUMPTION? DISABLED PEOPLE AND ONLINE SHOPPING

The Internet will extend the electronic marketplace and become the ultimate go-between, the universal middleman. Often the only humans involved in a transaction will be the actual buyer and seller. All the goods in the world will be available for you to examine, compare, and often, customize... We'll find ourselves in a new world of low-friction, low-overhead capitalism, in which market information will be plentiful and transaction costs low. It will be a shopper's heaven. (Gates 1996: 181)

E-commerce is without a doubt 'the hot topic of the moment' (Petrie and Colwell 2000: 16), perhaps an indication of the new orthodoxy that 'it is the aesthetics of consumption that now rules where the work ethic once ruled' (Bauman 1998b: 32). Far from being seen as a trivial activity, shopping is now considered a much more important phenomenon by academics (Bauman 1998b; Falk and Campbell 1997; Miller 1998). It should not then be approached as 'a thing in itself', but as a phenomenon which 'may lead much further towards understanding social relations and their nuances than might be expected' (Miller 1998: 4).

It is suggested that in a consumer society 'there are inevitably two kinds of slaves: the prisoners of addiction and the prisoners of envy' (Illich 1973: 46-7). Whilst disabled people, because of their relative poverty, are on the whole, 'prisoners of envy', disabled people's movements are increasingly seeking to make them the other kind of slave - 'prisoners of addiction'. The disabled people's movement in the UK has focussed less on securing consumer rights than has the Independent Living Movement (ILM), its American counterpart (Barnes 1996; Driedger 1989). However, as Barnes (1991: 224) suggests, BCOOP and its member organisations *have* borrowed from such right wing ideologies in seeking to enable disabled people 'to expand their role as consumers'. We should not however 'conflate consumerism and empowerment'

(Small and Rhodes 2000: 221). Whilst few of the research participants were in a strong enough financial position to exercise the 'consumer sovereignty' celebrated by Americans like DeJong (1983), in today's society it is becoming impossible to make do without consumption, 'not just for the average consumer, but even for the poor' (Illich 1978: 10).

There have been major changes in the last few decades in the way that people obtain the food they need. Even supermarket shopping is a relatively new phenomenon, and one that has not necessarily assisted disabled people. As with the introduction of self-service petrol stations, disabled people were overlooked 'in assessing the economic good sense of arguments for the change to self service' (Topliss 1982: 110). We are now often forced out of our local communities when hunger strikes, since recent years have seen the rise of the out-of-town shopping centre, and the increasing closure of smaller local stores (Mintel 1999a).

Whilst physical access for disabled people is much improved in these newer retail parks, access to cars is almost obligatory. Whilst the private car is now the most popular means of getting around, disabled people tend to have less access to cars (Heiser 1995). Households with a disabled member are only around half as likely to own a car as those without a disabled member (Barnes *et al.* 1999). Access to cars is also strongly age related. For those aged 85 and over, only around one in four people have household access to a car (Jarvis *et al.* 1996). Hence many disabled and older people are reliant on others to take them shopping, or to go shopping on their behalf. Shopping without assistance presents particular problems for older disabled people: 40% of disabled women over 65, and almost a third of disabled men in the same age group, find unassisted household shopping an impossibility (Jarvis *et al.* 1996). As Patrick explained, help with shopping often comes at a price: 'If you get a home care to do it... it's more expensive!'

It seems that shopping could yet again be undergoing a transformation. The hype suggests that 'consumer shopping will never be the same again' (de Kare-Silver 2000: 1). Consumers are now more likely to purchase products and services over the phone (Henley Centre 1996) and a dramatic expansion in teleshopping opportunities seems

likely in the next decade, perhaps based around 'virtual reality' computer technology (Johnson and Moxon 1998). According to one management text:

All the evidence points to an unstoppable momentum, an inexorable force that will drive electronic commerce forward and reach out to make it so pervasive and accessible that it can't fail to impact shopping habits. (de Kare-Silver 2000: 7-8)

It is still very unclear however to what extent shopping habits will change. The Internet is predicted by some to account for only 2.5% of all retail sales by 2003 in the UK (Cowe 1999). Others suggest that even a 15% drop in high street sales could make many stores unprofitable, so that in as little as thirty years time, there may be no shops at all (de Kare-Silver 2000). The implications of such changes for disabled people are equally unclear.

Teleshopping is often regarded as a positive move forward by those assuming a medical model of disability, as it meets the twin goals of cutting 'care' costs and increasing user self-sufficiency (Johnson and Moxon 1998). Hence the unquestioned assumption is made that 'E-commerce offers obvious advantages for physically disabled or elderly people' (Van Der Zee 1999: 14). Others claim it could have particular benefits for those with visual impairments (Petrie and Colwell 2000). There are however various problems with this way of thinking (Sheldon 1998b). These will now be considered.

E-commerce necessitates the use of credit cards, luxuries not granted to those with limited means. Hence the least affluent among the population who are without payment cards are 'obviously excluded from remote transactions based on electronic payment' (Mintel 1999b: 18). One of Kathleen's criticisms of the COL project was that the organisers had not considered such issues:

Kathleen

The principle is brilliant, absolutely brilliant for disabled and elderly people... But a lot of the people on the project were frightened because you have to have plastic... it was the only way you could pay. Some people such as Curtis went ahead and got the plastic so he could do it, but a lot didn't. Whether they'd no bank accounts or what, we

just don't go into it. But you shouldn't give with one hand and not tell them what they're going to have to do initially.

Since many disabled people are also excluded from remote transactions that would necessitate the purchase of expensive computer equipment, it seems that a return to more local shopping solutions may be called for, since nowadays: 'Instead of depending on cars, people will be depending on PCs and credit cards, and those who don't have them will still have a hard time getting fresh food' (Freely 1998: 2).

The COL project had a supermarket partner who offered a home delivery service to participants ordering goods over the Internet. This service has now been made more widely available, in line with Mintel's (1999b: 9) suggestion that the 'biggest online market seems certain to be grocery'. As with many aspects of communication systems, while some research participants were positive about the potential of e-shopping, they often experienced practical problems. Others expressed preferences for more traditional ways of purchasing goods, and often imagined future pitfalls that e-shopping could create. Several were not averse to the idea of remote shopping however, and some of the male participants often used mail order to purchase goods such as records and clothing. Frank for example did not like the idea of ordering goods over the telephone, but does buy himself clothes by mail order rather than 'messaging about in shops'. Patrick, like many disabled people, cannot buy himself clothes 'off the peg'. Instead, he orders them over the telephone from a specialist supplier, paying for them with his credit card. Both Frank and Patrick however were unimpressed by the idea of ordering household goods over the Internet.

In contrast, many of the participants were enthusiastic about online shopping for groceries, at least in principle. This enthusiasm was largely based on the barriers encountered by disabled people in making conventional shopping trips - arranging transport and assistance from other people, getting home with shopping bags, and dealing with negative attitudes:

Neil

It's good for disabled people yeah. If they can't get out or [whatever]... It's hard to get there like to do the shopping. You need to go with somebody or you need to arrange transport so you can get there, and somebody to go round with you to carry the basket, and you've got to carry all those bags home. And you can just go on City-on-Line! I think it's a great thing that. Can't be bad can it?

Graham

It wouldn't be so bad. I mean especially after days like this, you know.

Peter

[laughter] Yeah - easier than just trundling round t' shop.

Neil

Yes - it's no good at all. Now you can do it in comfort. You know, you just order what you want.

(fg2)

Danielle

[It] is really good for disabled people. Because they're picking what they want off the shelves, and not asking home help to go out and get it, or feeling like they have to go to that supermarket and get you know looked at, or you know snide comments made and stuff like that. And then having the hassle, and basically having enough, and not basically doing all your shopping because you just want to go home and cry.

Others like Kate, a mother of three talked about online shopping in terms of increased independence for her, and positive gain for her family:

Kate

It gave me independence. It meant that I could perform a complete task on my own without having to ask somebody to help me in some way. But it also meant that it helped us as a family because we gained family time... rather than spending family time at a weekend doing the shopping. You know, that was good for us as a whole, and that was a really positive thing.

For Curtis too, e-shopping meant he was no longer reliant on others to shop for him, and hence had more control over what he purchased:

Curtis

On the computer, you can pick what you want off the screen. If you see anything you can get it. If somebody else does your shopping you have to rely on them. I make a list out for them, but it's not the same.

Kate was perhaps the most enthusiastic about online shopping and seemed keen for it to develop further. It is suggested that online shopping is most popular amongst those who are money-rich and time-poor (Mintel 1999b). Kate was perhaps the research participant who most closely fitted this description, because of her class and her busy family situation:

Kate

I think I'd really like to see the shopping facility developed into... lots of different shopping facilities. I mean, I know Harrods are on the Internet and you're supposed to be able to shop, you know buy clothes like that, but I'd like to see that developed. I mean it's all fairly primitive. I'm sure they could develop that loads. Like your virtual reality sort of shopping experience.

Online shopping: Problems

The expressed enthusiasm for online shopping was not matched by the actual use of the facility by participants in the COL project. Some had been unable to use the shopping facility because of its complexity, and a lack of adequate training. Others were put off by the expense and the loss of social contact that online shopping would inevitably create. When people did use the facility, it seldom lived up to their expectations:

Kathleen

I expected that you'd walk down a supermarket aisle, and see what you wanted - like being in a game - and you'd walk down the supermarket, see above you what was in that aisle, and pick off the shelf what you wanted. No! It's a list of commodities. So you pressed on the department you wanted. You did pick it up and it did appear with a can. But everything was the same shape - it was a can... I really expected to go into a supermarket and walk down an aisle and get stuff off shelves... I think it could have been done.

Those who had ordered their groceries online often reported not only that it ended up more expensive than actually visiting the store, but also that it was a slow and often frustrating process. These themes will now be considered.

According to one commentator, 'the e-shoppers of today are less interested in price than in convenience' (Cowe 1999: 16). However, many shoppers are motivated by thrift - 'the specific search for lower prices based on systematic comparative shopping' (Miller 1998: 49). According to Daniel Miller (1998), this is especially true of older people. He illustrates this using the example of Mrs Lloyd, 84 years old and recovering from a knee operation, who is helped to the supermarket by her daughter. Her primary aim when shopping is to find 'specials' - products that have been marked down in price. Online shopping for groceries does not allow the practise of this kind of thrift, making it an unpopular idea amongst many of the research participants:

Frank

I mean wherever you're going shopping nowadays - buy two and get one free. There's that many gimmicks to get you to buy things. Which if you're ringing it up over t' phone or on t' computer you don't see them things.

Those who had used the online shopping facility had similar criticisms:

Kate

I've found it to be more expensive... when I do my shopping, I shop by special offer... I see what's on offer and I think: 'oo - I'll have two of those' [laughter] ... you shop in a different way. So you're not able to economise in the same way.

Supermarkets can be high or low cost. Kwiksave and Poundstretcher for example are cheaper than Tesco and Sainsbury (Miller 1998). The supermarket partner in the COL project was high cost - a curious choice for such a project. Consequently, some were put off by the high prices. A £5.00 delivery charge was also payable, a particular barrier for those who were living alone:

Edith

I looked at the shopping, but what shopping do I need? I can't afford to shop there with being only one. It'd cost... five pound, and I only spend about five pound on food. So I didn't bother about shopping.

Doreen/fgl

Well one firm that advertises charges you £5.00 for delivery. Another firm that advertises, you've got to order £25 worth of goods, which is no good if you're living on your own.

As described above, it is often suggested that those who would rather shop online tend to be money-rich and time-poor - hardly an accurate description of the majority of disabled people, who are financially disadvantaged, and often have time on their hands. In any case, those using the shopping facility often complained that it did not actually save them any time at all. It took Kathleen around two and a half hours, which was often longer than a trip to the supermarket. Kate also highlighted how online shopping was a difficult and slow process, albeit one that conserved her energy for other things:

Kate

You know, you're weighing up so many things - different makes and the size, how you cook something - which you can't tell. You've only got the name of the products. You only ever buy products you've bought before because you can't try new things, because you haven't got a list of ingredients so you can't see what's in it. A lot of people have dietary needs, so you can't make those informed choices... I want to be able to click on a product and get more information. And it makes it a long process to do it. I found that to do my shopping, working quickly on the computer, from start to finish it took me two hours. To leave here and come back from Morrisons takes me two hours. It only took me the same amount of time, but it seemed very different. And I felt I'd gone through a lot of process to actually make it happen. I hadn't lost any energy though... so that was good. And I'd been able to do it all myself which was good. I think the idea of it is brilliant. I think the actual idea of it is. It needs developing though to make it really accessible and useful to people.

Martyn placed an order only once. He did not get the correct goods delivered, and has never ordered again. Both Kathleen and Kate were also frustrated by receiving incorrect orders. In Kathleen's case, the technology was blamed. Kate blamed herself:

Kathleen

I never got an order correct. Never! ... if you ordered two bottles of coke, you'd only get one; four yoghurts you'd get two. I once ordered a pound of apples - I got one apple! And last time I got the beginning of the list and the end of the list. All the middle bit was out... I think technology has not quite got to supermarket shopping.

Kate

I found I made mistakes. Like when you're ordering fruit and vegetables you can't at that moment order how much you want. You've got to remember that when you come to the checklist you have to then put the quantity in. And so, one time I ordered potatoes. I thought I was ordering a bag. In fact they delivered me one potato... The sizes of things, you're not always [sure about]... So you sort of look at what sizes

there are, and you sort of think 'well - it's probably that middle one'. You end up not getting the things that you want. So that I found hard.

Kate's point about actually seeing products was often raised by those who preferred to shop in store. The inability to touch and try goods is one factor said to restrict the usefulness of remote shopping (De Kare-Silver 2000), and participants often thought it important to see what they were buying before they handed their money over:

Maude

I like to go and see what I'm buying me. Particularly for older people. They want you to shop through a telephone, but how can you do that?

Patrick

Well you can't do that [shop for food] 'cos you don't know what you really want until you go there... You want to see what you're buying don't you?

For those with visual impairments, like Helen, being able to inspect the goods was just as crucial:

Helen

I like to be able to prod my apples and bananas before I buy them to make sure they're OK. I like to inspect them to see if there's any wormholes in them or anything [laughter]... Carrots and things, and tomatoes are really important to sniff, and mushrooms... You can't make sure that the tin isn't dented before you pull it off the shelves when you're doing it down the modem.

However, the main concern about shopping over the telephone or via a modem was that the social aspects of going shopping would be lost. This area will now be considered.

Just browsing: Shopping as a leisure activity

Shopping is now one of the nation's favourite leisure activities, with around a third of British adults shopping for pleasure (Mintel 1999a). It is suggested that shopping excursions may give a sense of belonging to a larger community, whether or not purchases are made:

The chance meeting of an acquaintance, the tactile but not too physical interaction with a crowd, the sense of presence and social centrality - of something happening beyond the close world of oneself, motivates many who are marginal, alone or simply idle to visit shopping centres as passive observers. (Shields 1992: 103)

Shopping then is 'a social activity built around social exchange as well as simple commodity exchange' (Shields 1992: 102). Older women were especially likely to talk about shopping in these terms:

Dot

I don't think [I would ever shop online] 'cos I like to go shopping. I like to go and do me own shopping. And I go every Sunday. I've a friend takes me on a Sunday. We go to Morrisons, have us lunch and then shop. I enjoy that.

Maude

To me, if I'm shopping I want to shop.

Nancy

That's where you meet people.

Maude

It is. I don't agree with shopping through your computer. I think you'd lose a lot that way. I like to go out and I like to 'ave a good browse. It's an outing. That's it - it's an outing.

Those preferring to use the Internet for shopping are more likely to be male (Mintel 1999b). However, some older men like Martyn were of the same opinion:

Martyn

I would actually prefer to order in the actual store itself because I could get a cup of tea, and I could meet people in the community.

It seems then that the use-value of online shopping is undermined by the fact that 'human beings are social animals first and passive consumers second' (Naughton 2000: 8). Shopping was a valued trip out for many of the participants, and provided an opportunity to meet people. Consumption was often secondary. Maude for example highlighted that shopping was not necessarily about making purchases. She likes to browse: 'I save loads of money that way!' This aspect of the shopping experience may be particularly important for disabled people whose opportunities for leisure activities are severely limited. It is also an aspect that remote shopping cannot provide. Hence it was a matter of concern for many that their opportunities to go out shopping might decrease with an increased emphasis on online shopping.

Online shopping and the technical fix

In Peter's opinion, a rise in online shopping would have a major effect on retailers: 'they'll go out of business basically. No point in opening the shop up'. He seemed unconcerned however about the implications of this for disabled people, or for society as a whole. Others voiced concerns that a rise in online shopping for disabled people might open the door to yet more segregation, and that they might be sidelined by yet another technical fix. As participants in fg1 suggested:

Doreen

It's getting taken out that people want, not getting things delivered really.

Sylvia

Not just to be shut in your house to order things. Better if you can go out and see things yourself. It's better transport people need and better facilities for getting in and out of shops.

(fg1)

Max felt that he was already being discouraged from actually visiting shops, and being pushed into ordering over the telephone. He was understandably aggrieved by this:

Max

I personally think that teleshopping is just keeping disabled people in their houses I suppose... I think [supermarkets] need to be kicked up the arse personally. You know, we go there, we say we want someone to help, go round with us. We want somebody to tell us the bargains. We want someone to tell us where stuff is, the sizes of stuff. And why shouldn't we? I don't like it a lot of times. And sometimes you hang round for a bit - 'oh could you book it' and all this. 'No - why should we have to book it? You don't book it when you go shopping so why should we?' And you don't meet people... if you're indoors all the time... There's a place for it, and I think it's useful, but it could be more segregating somehow. I had the same sort of conversation with the manager at Iceland - you know Iceland deliver now. I said 'well we'll come along with the [guide] dogs'. 'Well you know, do it on the phone and we'll bring it to you'. I said 'yeah - but I wanna come'. 'Yeah but it's not very good facilities - yeah we do allow dogs in but, but' - you know, but this and but that.

Hence it seems that whilst online shopping has potential for disabled people - at least once certain problems are ironed out - rather than extending autonomy, it could represent another way of confining them in their homes, reducing their social contact, and limiting their opportunities to shop in more traditional ways. As Caroline suggested:

Caroline/fg3

You've got to have the lot! You've got to have the choice! Whether you decide to sit at home and do it or whether you want to go out and do your shopping yourself and squidge the bits of meat, or decide you'd rather have somebody else choose it for you. ... that's the point. You've got to have that choice.

At present, disabled people do not have this element of choice. Even those with Internet access who wish to access information, or purchase goods online, are often prevented by the inappropriate and exclusionary design of web sites. The sticky subject of regulating the Internet will now be briefly considered.

FREEDOM OF INFORMATION: REGULATION AND ACCESSIBILITY

At present, the web is relatively unregulated. Policing the Internet at a national level is problematic because of its global nature. There is reason to believe that this may be changing however, as national governments and international organisations find new ways to exert control. In a recent landmark ruling for example, a French court has ordered *Yahoo!* to block French Internet users from accessing its auction sites selling nazi memorabilia. Whilst welcomed by some, the ruling is seen by libertarians as a direct challenge to freedom of information/speech on the Internet (Guardian Unlimited 2000). Such challenges may do little to assist disabled people, since organisations such as WIPO are arguably 'about controlling and maintaining the interests of the powerful, the rich and the elite' (Darke 2001). As will be further discussed in Chapter Eight, Leonard Cheshire recently appealed to WIPO and successfully shut down disabled activist Paul Darke's www.leonard-cheshire.com site, which was openly critical of their activities.

Freedom of information was an issue for participants and organisers of the COL project. Although participants were told to use the computers in any way they chose, it seemed that accessing information of a sexually explicit nature was not deemed acceptable by those in charge. During a phone call with the project leader, he complained that one participant had been sending 'inappropriate' messages to other participants about viagra and SPOD. When clearing the same participant's mailbox, he had also apparently found e-mail messages from 'adult' web sites. The situation was possibly even worse for those accessing the Internet in resource centres, where disabled people are often denied privacy (Shakespeare 1996b). Barnes's (1990) study

of younger adults using day centres showed that discussion of matters sexual was a 'no-go area', largely due to the attitudes of social services managers. Hence, an outreach worker informed me that Christy Brown Resource Centre had installed 'nanny-net' on their computer - a mechanism which blocks any information of a sexual nature. Other centres had not followed suit however, and at Stanmore Hill, a woman frequently used the COL computer to access information about sexuality, sexual health and so on. Here, the computer was sited in a small, relatively private room specifically to allow such information gathering activities.

Use of the Internet by disabled people to access sexual information and pornography is undoubtedly an area which merits further investigation. It was not however an area which I felt particularly comfortable inquiring about during the fieldwork. Neither was it an area about which people volunteered information. Kathleen was one of the few people to raise the issue. She had been shocked by what she found when searching the Internet for information about holiday activities for a disabled boy of eleven:

Kathleen

I put child with spina bifida, 'cos there's always an age group. And it came up with a list, and one of them was sex. Now I could not believe my eyes. I printed it off and I told the mother what it had come up with, because I was horrified... I had specified an age group and that's what it'd come up with! I didn't know where to go. I wanted to tell somebody that that shouldn't be happening, 'cos people say it's so easy. But to put an age group on and then [have] that come up was - it was sick.

The subject of regulating the Internet is a contentious one then, with vocal adherents on both sides of the debate. Whilst such issues are largely beyond the scope of this study, one area of regulation is crucial to disabled people - how to ensure the accessibility of web-sites for all potential Internet users.

Discriminatory web design creates major barriers which prevent disabled Internet users from accessing information, particularly those with visual impairments (Petrie and Colwell 2000). Whilst none of the visually impaired research participants were

using the Internet to find information, Melanie highlighted the problems that she encountered:

Melanie/fg3

One problem with the Internet is that it's very mouse orientated and for those of us who can't use a mouse, you're stuck... So you can't look up anything personal unless you've got a friend or somebody who can help... I'd like a touch thing on the screen, or a keyboard.

To date, it seems that web accessibility may be higher on the political agenda outside the UK. Section 508 of the United States Rehabilitation Act Amendments of 1998, for example, requires that all Federal Government agencies must make their electronic and information technology accessible to disabled people, including employees and members of the public. Although this legislation only forces US Government agencies to ensure that their web sites are accessible, there is talk of it being enforced for all government contractors (Wheelwright 2000). Similarly, in Australia, Bruce Maguire, a blind Internet user is currently pursuing a legal action over the inaccessibility of the official Paralympics site. This case could set an important precedent in the United Kingdom, where similar action could be taken under the DDA. As an RNIB spokesperson has warned: 'Web designers here should think very carefully before making an inaccessible site, as they could find themselves on the wrong side of the law' (White 2000: 8). Some commentators are optimistic that positive change in the United States and elsewhere will inevitably trickle down to disabled Internet users in this country (Clarke 2000). However, we cannot afford to be complacent about this. As discussed in Chapter Four, we cannot merely depend on the altruistic impulses of information providers to extend their services to all. For disabled people's informational rights to be fully respected there must, at the very least, be appropriate legislation and regulation. As Jessica told me, laughing at the sound bite, 'information is a right not a privilege'.

SUMMARY

Disabled people face a number of barriers to accessing commodities such as information and household goods. Communication systems have great potential as an alternative means of access, but need developing technically before they will be truly useful to the majority of the disabled population. Some form of regulation seems necessary in order for this to take place. At present, only the minority is benefiting, and even this elite may find that they are excluded by discriminatory web design. The unconnected majority of disabled people may find that accessing information and other consumer goods in traditional ways becomes even more problematic as these facilities become more available online. The Internet is not then the panacea that many suggest. There is still a need for appropriate and accessible information to be disseminated to disabled people in other ways - preferably information that is controlled by disabled people and their organisations. Such information services must be funded as a matter of priority. Likewise, efforts to improve access to shops, transport systems and the wider environment must be stepped up if a technical fix is to be avoided. Shopping is an important leisure activity and source of social contact for many disabled people, and without such measures, they could become further isolated, and even less able to exercise autonomy.

Whilst there were fears that the use of communication systems to purchase commodities might create further isolation, the fieldwork demonstrated that one of the most important use-values to which such technology can be put lies in its ability to *reduce* feelings of isolation. It is to the important area of interpersonal communication that we will now turn our attention.

CHAPTER EIGHT: NETWORKING FOR CHANGE

Many disabled people have little contact with others and live very isolated lives. In this chapter, the potential offered by communication systems for reducing the isolation of disabled people, maintaining contact with family and friends, and for forging new relationships will be critically evaluated. Communication systems are not considered a substitute for face-to-face contact, and the relative merits of different communication media will be considered. Whilst the telephone was the system most commonly used by the disabled people involved in the fieldwork, those with access to the Internet frequently described its most salient use-value as its potential to facilitate communication with others. Notions of community will be discussed in relation to computer mediated communication (CMC), as will issues of identity and 'passing' as non-disabled. Finally the potential for ICTs to facilitate the cultural and political development of disabled people will be considered, especially in relation to the growth of a global disabled people's movement.

GET A FRIEND, GET A LIFE: THE BASIC NEED FOR SOCIAL CONTACT

As well as the basic human needs discussed earlier, there are other societal needs, the satisfaction of which is necessary to enable basic individual needs to be met (Doyal and Gough 1984; 1991). Communication is one of these. We cannot for example learn to exercise autonomy in isolation from others, since 'successful *individual* action is always predicated on some form of present or past *social* interaction' (Doyal and Gough 1984: 18). We must all have the opportunity to participate in society, as there are serious consequences for those who are prevented from doing so. Peter Willmott suggests that personal relationships with friends, family, neighbours and colleagues are critical in every society and that the 'type, range and proximity of

social networks crucially affects a person's quality of life' (1986: 122). Ray Pahl (2000: 95) continues on this theme:

We are less likely to catch colds if we have friends; we are more likely to recover quickly from cardiac arrests, and we are less likely to suffer from various forms of mental ill-health. Those with better social support are better able to cope with stressful events and circumstances. So friendship may be a highly significant art of life enabling us to be happier and healthier with greater self esteem. Get a friend: get a life.

For disabled and older people, the opportunities to satisfy such needs are severely impeded. Many have little contact with others and live very isolated lives. This area will now be examined, drawing on the experiences of those who participated in the fieldwork.

DISABLED AND OLDER PEOPLE AND ISOLATION

In a recent Mori poll commissioned by Help the Aged, 10% of people aged over 65 were deemed to be 'acutely isolated' (Carvel 2000). Ill health was found to be an important determining factor, with 31 per cent of over-65s with a 'long-term illness' feeling isolated (Disability Now 2000a). Poverty also played a key role (Carvel 2000; Disability Now 2000a), a particular concern since the number of pensioners living in poverty has risen by almost 100,000 since the 1997 election (Disability Now 2000a). Victor Meldrew was a famously embittered pensioner in the popular sitcom *One Foot in the Grave*, and the increase in suicide rates amongst the 'post-Meldrew generation' of isolated older men is now beginning to be a concern. There are 25 deaths per 100,000 among men over 85 compared to just 9 for men aged between 15-24 (Summerskill 2000: 4).. This increase is attributed to isolation, and factors such as transport disability also appear to play a part. As one commentator suggests, 'When people can't visit friends, or friends don't visit them, they become more and more isolated. Life loses meaning' (Tessa Harding, in Summerskill 2000: 4).

Isolation 'is a phenomenon disabled people share with elderly people in general' (Heiser 1995: 55), with disabled people under 65 often experiencing a similar shortfall in their social lives (Barnes 1990). Hence it is predicted that the isolation of disabled and older people will be 'one of the biggest social problems' in the twenty first century (Harbert 1997a: 6). The means for these groups to achieve socialization are scarcer than for the general population - 'another reflection of our oppression' (Heiser 1995: 55). As Kuhn (1984: 9) suggests, it is ageist oppression which 'makes old age lonely and despairing'. Since many disabled and disabled older people still face barriers to such taken for granted social activities as meeting friends in the pub, segregated provision often provides the only opportunity for meeting others outside the home.

A recent study suggests that those attending day centres 'felt that this was the only way they had of breaking isolation and making contact with other people' (Vernon and Qureshi 2000: 264). This was born out by the fieldwork. The resource centre was often described to me as a 'life-saver' - a place where people could meet others and rebuild their self-confidence, and a welcome opportunity to spend time out of the house. Patrick for example, experienced considerable emotional distress on losing his wife seven years previously, but meeting other people at the resource centre he has since started attending has helped to alleviate his loneliness and isolation:

Patrick

If I didn't come to a place like this, I'd be having to just see four walls. It does get me out of the house coming 'ere. You know, you don't see nobody else, nobody at all... I meet people 'ere.

The resource centre does not suit everyone however. Kate was once invited to Stanmore Hill to lead a morning session about the COL project. The session was postponed until the afternoon, leaving Kate confused by her role - was she there to help or to be helped? She found this hard to deal with and left before the afternoon. For her, the MS Therapy Centre serves a similar function:

Kate

I feel a very important link for me is going to the MS Therapy Centre and actually meeting with other people and being able to talk with them. It feels like something proactive.

Other sources of contact for many disabled people who live alone, are those who support them in their homes - the sheltered housing warden, the home-help and so on. Ayesha Vernon and Hazel Qureshi (2000: 263) maintain that:

social contact and company are valued because they prevent isolation and break the monotony of being confined in the home with nothing to do. For some older disabled people who are housebound and live alone, having a chat with their home help can be as important (if not more so) as the performance of the practical tasks, particularly as this is often their only form of social contact.

Frank was seventy-seven when interviewed and is a widower who lives alone. He has limited contact with neighbours in his sheltered housing complex, but sees people at Colliers Resource Centre which he attends twice a week, has family members who live nearby, and looks forward to fortnightly visits from his home help: 'you can 'ave a little natter and a bit of fun with 'er and I enjoy seeing 'er'.

Because of their continuing exclusion then, in order to satisfy their need for communication with others, disabled people are often forced into dependency on segregated transport to take them to segregated day centres. Their social circle sometimes consists only of those who are forced into a similar position, those paid to assist them in their homes, and family members. Radical changes are required to remedy this. In the absence of such social transformation however communication systems provide another means of connecting with people, a means which circumvents many of the barriers to disabled people's mobility. The use-value of the telephone has already been discussed in relation to security, and information gathering. Here, we will consider its use-value as a satisfier of the need for communication. More recent innovations, namely video conferencing and CMC will also be discussed. First though, is this mediated communication an effective replacement for actually *being* with others? This question will now be considered.

MEDIATED COMMUNICATION: EFFECTIVE REPLACEMENT OR USEFUL ADDITION?

Helen

[Talking on the telephone] doesn't replace personal contact. It's just a substitute at times when you can't... get that. I mean even if I 'ad a long conversation on the telephone every evening for a month, but didn't actually go out socially with anybody, or have anybody in the house socially or whatever, I think I would feel that. 'Cos it isn't the same as being with somebody.

Even when the telephone does not present difficulties in terms of accessibility, many of the disabled people who talked to me expressed a preference for face-to-face meetings. Talking on the telephone is not an effective replacement for physically being with people. The same holds for computer mediated communication. Bill was particularly concerned about the isolation that dependency on CMC might engender, and was critical of the government's role in championing such developments:

Bill

Communication with another human being is summat that a machine ain't gonna compete with, and it can't compete with it no matter 'ow good that machine is. And that's what they're trying to do. But it i'n't gonna work - it'll never work. You've gotta go out there and you've gotta live your life, live it to t' full. And if you don't you'll end up being pissed off, bored, sat in front of computer all day, and what for at end of day? For nowt! Just because some government had an idea and thought it'd be good.

So why is face-to-face contact so often considered superior? According to the social psychological literature, face-to face interaction is typically characterised by a number of different sensory cues, both verbal and non-verbal (Short *et al.* 1976). It is these cues which make face-to-face interactions 'inherently richer than mediated interactions' (Brook and Boal 1995: vii). The standard telephone has traditionally

restricted communication to the verbal channel, hence permitting a less rich form of interaction, and excluding many people who have other requirements. Amongst the non-verbal modes of communication excluded by telephone conversations are visual languages such as BSL, the cues required for lip-reading which are indispensable for non-signing Deaf people, and additional factors such as appearance, proximity, facial expression, direction of eye-gaze and so on. Non-verbal communication may have consequences for the effectiveness of mediated communication 'to the extent that it determines feelings of Social Presence' (Short *et al.* 1976: 157) - a phenomenological variable affected by a variety of cues which affect the 'apparent distance' of others. Communication media having a high degree of social presence are judged to be 'warm, personal, sensitive and sociable' (Short *et al.* 1976: 66), and are thought to be more effective for particular kinds of communication, including those concerned with interpersonal relations. Face-to-face interaction is however still thought superior in situations involving a high degree of emotional contact or intimacy. It seems then that a sole dependence on mediated communication may not be effective in reducing isolation.

As will be discussed below, video telephony may more closely approximate face-to-face interaction than speech only systems, and thus be more effective in reducing isolation. Even here however, a myriad of cues are absent, including touch (vital in the language used by Deaf-blind people), and smell. However, even those with visual impairments are said to benefit from video telephony, since it can be used as a 'remote eye' - objects or printed material can be shown to sighted people who can then describe them verbally (Lindstrom and Pereira 1995: 115). E-mail, in contrast, supplies only textual information, offering very little in the way of social presence. It seems though that this may be welcomed by some disabled people. The use-value of telephones, video conferencing units and CMC in satisfying the need for affiliation will now be considered:

'IT'S GOOD TO TALK: TELEPHONES AND AFFILIATION

Joyce

I mean yeah, really I don't know what we did without 'em, you know. Because if you're feeling lonely you'll think 'oh I'll phone so-and-so' and you can have a conversation. Like I'll phone Janice just for somebody to talk to...

Janice

I'm just somebody to talk to you know [laughter]

Joyce

Well you know what I mean!

(fg4)

As discussed previously, those interviewed were in agreement that the telephone is now an essential commodity. Almost as important as its use-value as a satisfier of the need for security (Chapter Six) was its utility in personal exchange and communication - what some refer to as intrinsic uses (Keller 1977). As before, the telephone's use-value for maintaining friendships and keeping in touch with family members was particularly important in light of increasing geographic dispersion, and the barriers that participants encountered socialising in more traditional ways. However, whilst it is acknowledged that telephone usage 'is an important factor in combating social isolation' (Harbert 1997b: 6), with poverty being a key factor in producing such social isolation in the first place (Carvel 2000; Disability Now 2000a), many isolated disabled and older people are reluctant to run up large telephone bills. Hence it may be more difficult for them to maintain contact even on the telephone (Harding in Summerskill 2000).

Maude lives alone and has no family members living nearby. She has a group of friends with whom she keeps in touch via the telephone, but - if Maude is making the call - only for the purpose of making arrangements:

Maude

We go on holiday... once or twice a year. And we might meet to go to a theatre, and I'll ring them for anything like that... But I will not chat for an hour. I do not believe in paying an hour's chat line - no way... if someone at the other end is paying, I'll stay as long as they want, but for me, just the bare essentials if you don't mind.

Maureen is similarly concerned about making expensive outgoing calls. She has been trying to cut her bill down, by limiting herself to more instrumental calls:

Maureen/fg1

This time we said, 'right... so-and-so's cut out. They never bother to give me a ring, so why should I keep ringing them?' So we cut it down... we rung the ones that we needed to ring like me daughter.

Many participants also reported a reluctance to give anyone their home phone number, thus limiting the amount of incoming calls they received. Patrick for example has minimal contact with anybody over the telephone - 'there's nobody rings me, 'cos I don't give people me number'. As Joyce suggested in fg4: 'You don't want everyone knowing your number. You don't know what calls you're gonna get!'. Maude agreed that 'sometimes it's abused isn't it? You get all these funny calls'. Nancy could barely stop laughing when she told me about one such call that she had received:

Nancy

They wanted to know what colour me knickers was [laughter]. I telled them they were red flannelette and 'ung up! [laughter]

It seems then that the telephone's use-value as a means to affiliate may be limited for some members of the disabled population. They may be unable to afford to call others, and concerned about others calling them. It is also suggested that factors such as gender may have an effect and that it may be more difficult for men to take

advantage of the telephone in this way (Livingstone 1994; Moyal 1992). Chatting on the telephone tends to be a female activity, with women's telephone use being characterised by 'a notable concentration on protracted intrinsic calling' (Moyal 1992: 304). This was to an extent supported by the fieldwork, with women more likely to prioritise intrinsic calls, and admit to spending a good deal of time and money talking on the phone. This was especially true of those women who were living alone.

Dot for example sees telephoning as an important leisure pursuit, and justifies the money she spends on phone calls by comparing it to what others might spend going out. Likewise, Helen sees it as a more economical way of maintaining friendships than actually travelling to see her friends in person, in terms of money, time, and energy:

Dot

It's a lot I know [my phone bill], but when you think, I don't go out drinking or anything like that, so money I'm spending on phone calls is only money I'd spend if I went drinking, to the pictures, bingo...

Helen

I know I can't be with my friends any more than I am, because all right, a two and a half hour telephone call may cost like four or five pounds, but to get down there by train! [laughter] And there's a time element - my friends work, I work. We all have other things going on in our lives as well. And sort of like, a dash down to [see a friend] on a Saturday morning to come back on a Sunday evening is just too exhausting you know.

Kathleen too is resigned to spending money on staying in touch. She lived abroad for some years and her children and grandchildren are still resident there. Calling the family then is not cheap. However, she admitted: 'I never think when I phone me family how much it's costing. It's talking to them that keeps me going.'

In contrast, Frank's telephone use is more instrumental:

Frank

I only use t' phone, you know, like when I rang daughter about cooking liver sort of thing! You know - things like that. I mean I'd never ring 'er up to ask 'er how she's going on. If I rang 'er up there's something I'd want to know about something.

His bills are correspondingly low: 'if it's over twenty pound, I'm wondering who I've been calling'. This low usage does not appear to be due solely to thrift however. He is equally averse to incoming sociable calls, appearing to view them as an intrusion:

Frank

The person that rings most is [a] woman who comes 'ere... And she's a bloody nuisance to be honest! You know... you'll be watching telly and then t' phone rings. And you'll get on t' phone and it's her on t' phone wanting to know what I've been doing, and - you know - load of rubbish! But she rings me more than what me daughter does, 'cos I think me daughters watching what bill's gonna be.

This seems to support Sonia Livingstone's (1994: 122) claims about men's telephone usage:

men regard the telephone with irritation, suspicion and boredom, they see little point in chatting on the phone, avoid initiating a call, and often prefer not to answer an incoming call.

Women however see the telephone as a 'lifeline', providing a vital source of emotional involvement and a connection with loved ones.

As well as being a gendered activity, it seems that social uses of the telephone may also be affected by impairment. It has been suggested for example that blind people may be more comfortable on the telephone than their sighted counterparts, being less reliant on visual cues and non-verbal communication (Rutter 1987). The visually impaired people who participated in the fieldwork agreed that the telephone was important for them, but were more likely to give other reasons - especially their exclusion from printed communication. Max for example considers the telephone a

particularly important way of keeping in touch for blind people, who may not have the option of writing or reading letters. As he commented 'if you're going to write a letter you've got to rely on the person the other end using a scanner or having someone to read it and they haven't always got that'. The only alternative to telephoning is sending a taped message through the post, something that Max does often. Helen too is an enthusiastic user of the telephone, and also enjoys sending and receiving taped letters. She agreed with Max that writing a letter is simply not an option.

Those with other impairments, gain less comfort from using the telephone. It may for example present particular problems for those with impairments such as aphasia: a reduced ability to express thoughts and feelings verbally, often the result of a brain haemorrhage. These difficulties can be further exacerbated when talking to strangers (Boazman 1999). Several research participants expressed similar anxieties about using the phone. The fieldwork also demonstrated problems for those with impairments effecting their speech or hearing, and there was often a tendency to restrict calls to close friends or family who they might understand, or who might understand them more readily. Some disabled people do not use verbal speech at all, giving a standard telephone *useless*-value. For them, communication systems using non-verbal channels, such as video telephony and e-mail, have definite advantages. The use-value of these systems will be discussed below:

VIDEO CONFERENCING

Martyn

I like to see who I'm talking to, because a lot of expression gives people away - you know what I mean? People are not very good at telling lies when you're facing them, but they are when you're not... I'd say within the next ten, fifteen years... you're not gonna have ordinary telephones any more, they're all gonna be screens.

Bill

I used the video link when I were on City-on-Line... it were a lot easier seeing the person, because I lip read sometimes. It were a lot better and a lot easier seeing the person for me.

Visual cues were often thought to be important by sighted research participants, especially by those like Bill who have difficulties hearing. They were also thought important in reducing feelings of loneliness:

Kathleen

I've no family in this country. It's nice to be able to talk to someone face to face instead of down a phone, and it's like them being in your home... I do feel as though you don't feel as lonely when you can see the person.

Whilst logic would dictate that provision of both auditory and visual channels may for some individuals result in greater 'social presence', there is no mutual eye-contact when using video channels (Short *et al.* 1976). Kate found this particularly distracting when using her video link:

Kate

Although you sort of think 'oh wow, you can see somebody', you can't really. It feels frustrating. It just feels like they're looking away from you. It doesn't feel as though they're actually paying you any attention, whereas they are really. I think it distracts from the conversation really.

Others, whilst not averse to seeing the person at the other end of the link, because 'you can see what they're like' (Andrew), were not keen on being seen themselves. In the film *The Elephant Man*, John Merrick is so horrified by his own appearance that he screams on catching his own reflection in a mirror. All mirrors are subsequently removed from the hospital where he is resident (Darke 1994). I was surprised to find Andrew equally reluctant to view his own image:

Andrew

I've seen pictures of people on it [the video conferencing unit], but I don't want to go on it 'cos I don't like to see me own face. I don't like to see meself on camera really. I don't like looking in mirrors and that. I don't even like me own photograph taken.

Dot too would like to be able to see who she is talking to, but adds:

Dot

I don't like getting dressed when I'm not going out. I don't put me teeth in. I just put a caftan on and comb me 'air and that's me for t' day. So I wouldn't like people to ring me with t' video conference - 'aving to rush about, comb me 'air, put me teeth in, put a jumper or something on, make it look as if I were dressed.

The COL video equipment was fraught with problems, and finally only a handful of participants were able to use it. As Kathleen maintained 'I don't think technology has quite caught up with video-conferencing as yet!' The fewer people who are connected to any interactive system, the lower its use-value (Short *et al.* 1976). Hence, although Martyn's video conferencing unit is one of the few still functioning, it is now virtually useless. He described his frustration:

Martyn

Video conferencing is A1, no problem whatsoever. I think it is brilliant. If it worked. First six months, no problems whatsoever, but as people's computers were going back, so were the videos, and now I think there's ...three of us that's still got it... so I've nobody to talk to. So I've got an expensive camera which I want to keep, and I want to use, but I've nobody to talk to.

Despite teething problems, it seems that video conferencing may have enormous potential for many isolated disabled people, since it has more 'social presence' than the standard telephone, and includes those people disabled by auditory systems. It remains an expensive medium however, making it less widely used, and hence, less

useful. In contrast, e-mail communication is expanding rapidly, at least amongst certain segments of the population. Whilst the 'social presence' of CMC is low, perhaps making it a less effective tool in reducing isolation, it has enormous use-value to those with certain impairments, and has great potential as a means of making links with like minded people around the world. Its use-value as a means of affiliation will now be considered.

COMPUTER MEDIATED COMMUNICATION

E-mail's lack of auditory cues can have enormous benefits for those with speech or hearing impairments. John for example had no means of immediate communication at a distance until he was provided with an Internet-ready computer by the COL project. Not surprisingly, he claimed this had changed his life for the better:

John

It has had a remarkable effect. The first job on a morning is to check my e-mail... I have got a few regular people who contact me. It is like an extended family.

Likewise, Curtis claimed that being part of the project had improved the quality of his life and helped to reduce his feelings of isolation: 'because I could get in touch with people on the Internet'.

As well as being an effective system for those who face barriers to the speech-based telephone system, e-mail can have advantages for those who are disabled by paper and print. Take Helen, who has a visual impairment and used e-mail in her last job:

Helen

I just thought it was wonderful! I really did. And I'd love to use it again! I really would. I can't explain what it was. I suppose it was just another means of

communicating... I don't know whether it was partly I could type it up, could spell check it, do everything on the computer - no messing about with paper and print.

It is also suggested that e-mail is a very accessible communication medium for those on the autistic spectrum because of its absence of either visual or auditory cues. Autism is a neurological condition, often characterised by difficulties in handling multiple stimuli. Its effects vary according to whereabouts on the 'autistic spectrum' those who have the condition fall. The Internet is said to allow those 'on the spectrum' to 'have the communication they desire while protecting them from the overwhelming overload of human presence' (Singer 1999: 65). Judy Singer further suggests that the 'nerds' who designed the Internet may well be on the autistic spectrum themselves.

Those without home Internet access were able to use the COL computer at their resource centre to send and receive e-mails. Very few took advantage of this free facility however. It seems then that e-mail does not suit all. As described earlier, it presents major barriers for many people, particularly those who have problems with reading and writing. Others, like Frank are simply unimpressed by such new developments:

Frank

[E-mail's] doing away with the old fashioned thing of writing a letter and posting it i'n't it? It's just a quicker way. But in that respect, you know ordinary people, I mean they don't want to be through straight away to t' majority of things do they? You know, to me a lot of these gimmicks, I can't see what they achieve. I can't honestly.

Some fieldwork participants considered electronic mail to be of little use, as they did not know anybody else with that facility. Maude for example is interested in having her own computer, but is unsure about the use-value of e-mail. She expressed some interest however in using the Internet to meet new people:

Maude

I don't think I'd bother about the e-mail. I'd just have it as a computer... I mean, I don't know anybody really that I could communicate with.... Unless I got really clever and could compute with people abroad and get in touch with them, which I know you can do. But... I don't know if I'd ever get that far. I'd have to see how far I went... I'd like to see if I could get really into it, you know... It'd just get me away from meself.

Telephone chat lines have existed for a number of years, charge extortionate rates per minute, and tend to be associated with dating, with names like *Gay Exchange* and *Singles Bar*. The Internet has legitimised low-cost, mediated meetings with strangers, at least for those with the money to afford the hardware. Some of those who took advantage of the computer facilities at their resource centres, were keen on the idea of using such technology to communicate with new people, but felt unable to do this without having access at home:

Danielle

A thing that City-on-Line has got is Chat Room. But every time I go in and think 'oh - I'll do it this time' there's nobody on there. So I think there's only like a certain time ... when the centres locked up... that that usually runs. So I mean if I had access to the Internet at home I probably would use it... And I'd probably use the live chat thing as well. You know, where they say 'this programme is live, and technology these days you can like e-mail us or you can visit our www dot point and talk to superstars' and all that [laughter]... I suppose if I had one at home, yes I probably would be talking to strangers on it.

Neil

I wouldn't mind using it, maybe if I was at home in me own home - using it to talk to other people or - you know on the video talk or just a general chat.

The potential for otherwise isolated 'housebound people' to maintain and initiate friendships from their homes is one of the main advantages said to be gained from use of the Internet and CMC (Bowers 1996; Haywood 1998; Rheingold 1994). There is a vast and expanding body of work devoted to the subject of computer-mediated communication, much of which focuses on its role in the creation of new (and better) forms of community (Rheingold 1994). A related theme concerns the liberatory potential of assuming new and fluid identities in these so-called virtual or cyber-communities (Rheingold 1994; Turkle 1999). Both these themes were apparent in the fieldwork, and will now be critically examined:

MEETING IN THE VIRTUAL COMMUNITY

Much of the hyperbole concerning the use of new electric communication systems in the late nineteenth century, suggested that they could facilitate 'the building of better, usually construed to mean more open and democratically accessible, communities' (Marvin 1988: 65). This tendency is alive and well in much of today's writings about CMC. Howard Rheingold (1994) for example is an enthusiastic advocate of the Internet's role in creating a new, utopian virtual community - a community untainted by 'the contaminating effects of physicality, prejudgement, or prejudice' (Avery 1998: 2). He is not alone in his boundless optimism. ICTs are described as 'the means of bringing marginalized people back into their communities' (Paveley 1999: 41), and commentators and political leaders alike share a commitment to 'the restoration of community through the enhancement of communication' (Robins and Webster 1999: 28). However, if these systems are regarded as a panacea,

it must be because an inadequacy, or a breakdown, in communication is regarded as the fundamental social problem that confronts us... On both sides of the Atlantic, the politicians of the Third Way seem to think that 'fundamental change' will really come about once we can talk properly with each other and enjoy a big one-world conversation. As if all the worlds problems were simply the

consequence of a historical communications deficit. (Robins and Webster 1999: 229)

Typically, even those taking such a critical stance to the new technologies, often uncritically proclaim their use-value for those who face barriers to leaving the home (Haywood 1998). The implication seems to be that people excluded from their geographic communities, will automatically be welcomed into communities in cyberspace - this despite the fact that 'community formation is intrinsically about creating difference', and drawing boundaries to define who is 'in' and who is 'out' (Brent 1997: 75). As Dona Avery (1998: 2) suggests for example, the social isolation of disabled people can now be relieved thanks to communication systems 'and the sense of community that is derived from them'.

To an extent, Avery's contention was born out by the fieldwork. COL participants were all given each other's e-mail addresses and encouraged to communicate with each other on-line. This inter-group exchange was often the most important part of their experience on the project:

Kate

I think the thing that really, really interested me the most, was contact with other people. Getting to know all these disabled people - it was just wonderful. And such a quick contact with the e-mail you know, messages backwards and forwards. Oh yes - that was what really switched me on.

Kathleen

The e-mails were very far and few between initially, 'cos I don't think we really knew how to use it, or for what purpose. But then when the e-mailing got underway, ah, brilliant! We were just e-mailing everyone with silly stories what we did yesterday. It was just a great way to keep in touch with people, granted disabled, but all have different types of lives. And it was a variation of some young people up to elderly people so we weren't just mixing with our own age category and own disability category, it was an expanse across.

Bill however was concerned that the project was restricting his social contact to those disabled people on the project, and that far from relieving his feelings of isolation, it was actually making them worse:

Bill

Keeping in touch with the other people, bringing all the people together - that were good about [City-on-Line]. But you don't have to stay in to do that, or its like saying 'oh look, you can have these disabled mates', you know what I mean? It's like saying 'you've got to talk to these people'... That were one o' t' things that I picked up on - one o' t' first things. The other like - 'cos I were keeping meself in, I weren't going out and God knows what, so I was losing contact from me mates. I was losing contact with them. But I could have called anybody... that were on City-on-Line. And I do appreciate that I could call anybody on City-on-Line, but the fact were, I hadn't realised that I could only call people on City-on-Line!

It seems then that reliance on CMC could potentially exacerbate the experience of isolation. However, the converse is also argued - that '(s)triking up a friendship across the network will lead naturally to getting together in person' (Gates 1996: 238). This was also supported by the fieldwork.

Martyn and Kathleen, did not restrict their computer mediated communication to people on the COL project, and had met new friends in 'cyberspace'. For both of them, these on-line friendships had eventually led to face-to-face meetings. I was interested to find out how these friendships had developed. Martyn described how he went about it:

Martyn

Have you heard of newsgroups?... I send a letter right. I pick out California, Pen-Pals, 40-plus-years. I don't want anybody young, you know what I mean. I'm not being funny or 'owt like that but I have more in common with people over 40 than I have with the younger generation... As I say, California, Pen-Pals, 40-plus-years, and Miscellaneous Writing. I put a letter in there, in each one of them, giving my web-site

address, tell them briefly what's on it, and if you want to write to me, my address is on the web site. Whoom! It goes all around California. Miscellaneous Writing goes from England to Timbuktu, China the lot. And Pen-Pals goes all around the world! And then I get letters coming through saying 'I have seen your web site I think it's nice... Would you like to write to me?' And I say 'yeah, OK' and I write, and that's how it's done. I never push meself on anybody right. If they write to me I reply. If they don't reply to me, then I don't push it, you know what I mean? So far I've been writing to about eight people regular for two years.

Martyn suggested that 'anyone I talk to on a computer is part of a world-wide community'. He was able to trace his mother, who had left when he was only two years old, with the 'help of the Internet and people on the Internet'. He claimed to spend around an hour a day on the Internet, but was eventually removed from the project, having run up telephone bills which the project manager deemed unreasonable. Similarly *Disability Now* (2000b) reports that a disabled woman with an unlimited time connection to Freeserve has been threatened with disconnection for using it too much. This is apparently not an isolated case. Luckily, Martyn was able to finance his own Internet connection when the project withdrew its support. Kathleen was not so fortunate. She found new friends in a similar way to Martyn, but saw these friendships flounder when her e-mail facility was withdrawn as the project fizzled out. Unlike Martyn, she had not yet been able to re-establish her links when we last spoke.

Both Martyn and Kathleen had one on-line friendship that developed into a face-to-face meeting. Martyn's was with the American woman, who had helped him to find his mother:

Martyn

We kept writing, and then she said 'I'd like to come over and meet'. She invited me over there first and I said no I didn't really fancy America, and I said why don't you come over here so I can thank you in person. And she made arrangements and she came in April. They've just gone. They spent eight days here - enjoyed it...And there

wasn't any difference... as soon as she came through she was relaxed. We were both relaxed 'cos we knew each other. I mean, we'd both talked about the past, both talked about problems. So we knew each other before she came across.

Kathleen met up with a hospital technician she had met online, who happened to be in the area on business. She has not been able to continue the friendship however:

Kathleen

Two or three times a day he'd e-mail me. And he had to come down to [the local hospital] to do some practical things there. Met and had a drink... And after that he went back home, e-mailed me, and I e-mailed him back. And my e-mail came back 'cos my external e-mails had gone down - from me seeing him! He'll just think 'well - she hated me'. He wasn't anything to look at but he was a nice person and we had a laugh - his e-mails were hysterical!

Kathleen and Martyn's experiences seem to support the view that 'relationships that begin on line rarely stay there' (Parks and Floyd 1996: 11), a tendency which has also been noted with regard to the telephone. The increased possibility for contact through one medium is said to stimulate demand for contact by another (Short *et al.* 1976). This was further supported by Kate's experience of using Livechat - a Multi-User Domain (MUD) developed by Microsoft, and available to those on the COL project. (MUDs are meeting places in cyberspace where users commonly select their own 'avatar' - a visual or textual representation of themselves):

Kate

I've used [Livechat] quite a bit with somebody, and I've built up quite a friendship with somebody and that had a knock on effect of us communicating in other ways as well. We sort of have fun together on the Livechat, and we talk together on the telephone, and she's been to see me a couple of times, and you know - that's been good. Obviously we both have mobility problems and we don't live near each other. She might phone me and sort of say 'how about us doing Livechat?' And in some

ways you might sort of say 'well - we're talking on the phone won't that do?' but it's almost like saying 'come and meet me'. It's a very different means of communication. It's socially different... It's 'let's go out and have a game of squash together' almost, you know 'lets go and do something together'... it just feels like a different social thing to do. It's good.

It seems then that the Internet could play a role in facilitating communication between people, providing virtual meeting places, and stimulating offline relationships - at least for those disabled people who can access the relevant equipment. Because of the lack of visual or auditory cues in CMC, deception about one's identity is also an option when meeting new people in cyberspace. Both Kathleen and Martyn were reasonably honest about their identities as people with impairments. Had they chosen not to reveal this, a face-to-face meeting might have been less enjoyable or even possible. This recurrent theme of identity and deception will now be considered.

'NOBODY KNOWS YOU'RE A DOG': IDENTITY AND PASSING

On MUDs one's body is represented by one's own textual description, so the obese can be slender, the beautiful plain, the 'nerdy' sophisticated. A *New Yorker* cartoon captures the potential for MUDs as laboratories for experimenting with one's own identity. In it, one dog, paw on a computer keyboard, explains to another, 'On the Internet, nobody knows you're a dog.' (Turkle 1999: 290)

In Gibson's cyberspace novel *Idoru* a feisty female character who the reader encounters only as an 'avatar', turns out to be 'severely deformed' and 'in almost complete denial of her physical self' (Gibson 1996: 285). Hence she never leaves the house, and does not wish to carry on relationships offline. This is becoming a common theme in such works of fiction, as well as in much of today's academic writings. It is assumed then that cyberspace offers the liberating possibility of constructing new identities, thus freeing people from 'the imposed classifications of

class, race, gender, or disability associated with material space and place' (Loader 1998: 9). The ability to 'pass' as 'normal' is thus opened up even to those with the most severe impairments, removing the stigma from their interactions with 'normals' (Goffman 1963). In many such writings, the blame is placed squarely with the impaired individual for their lack of friends. Only through 'passing' in virtual space can their situation be remedied. Howard Rheingold (1994: 26) for example suggests that:

People whose physical handicaps make it difficult to form new friendships find that virtual communities treat them as they always wanted to be treated - as thinkers and transmitters of ideas and feeling beings, nor carnal vessels with a certain appearance and way of walking and talking (or not walking and talking).

Furthermore, we all exist in a real world where such deception is not necessarily an option. How then is passing in cyberspace liberatory?

Only Martyn and Kathleen have been through the process of meeting friends online and having to describe themselves. Kathleen made no attempt to pass, and was frustrated that she was unable to meet any disabled people on-line. Martyn however was less direct about advertising his disabled status:

Kathleen

It's funny, because on this Pen-Pal [list], I put disabled - not one disabled person wrote... I'd looked specially. I'd been browsing, for disabled people to write to, albeit people single such as meself, albeit male or female or whatever. But are disabled afraid of advertising the fact? I don't know! But there wasn't any down... are we freaks because we're disabled? Do we not advertise the fact we're disabled? The truth doesn't hurt! Do you not put that you're disabled then just start writing 'and by the way...?' No! If you're not open and up front to begin with.

Martyn

I don't actually tell them. On my introduction on my web page there's a little bit about meself. So if I'm writing to somebody new or just talking, things like that you know,

then I say 'well if you want to have a look at me web page it's at blah blah blah', and then they know. So I don't actually say 'oh I'm disabled' or 'owt like that, you know what I mean? It just tells a little bit about the accident, and about meself. And then if they want to write to me after that they can. If they don't, they don't.

Martyn obviously enjoyed the fact that fewer assumptions were made about him in his online relationships:

Martyn

I can talk to them, you know, because I know they can't judge me, and I'm not actually seeing them, you know what I mean?... They accept me for what I am. They know I'm disabled, in a wheelchair. But they also know from some of the stories I send out - how laid back I can be.

Other fieldwork participants also mentioned the less judgmental attitudes that others might demonstrate if they were unaware of a disabled person's identity:

Danielle

People can't judge you when you're on a computer, when you're on an e-mail. They think of you as a person. It's only when they actually meet you, but there again then the bond's already made. It's not like talking down the phone, you know. You can usually tell... when somebody's disabled because of the voice. They might have a speech problem you know. But on a computer, on the Internet, there's nothing there... And I think that is a good way to try and introduce people - you know disabled people with non-disabled people.

Kate

[Disabled people] ought to have the right to be seen without prejudice... on the Internet people don't know that you're disabled. They ought to have that opportunity to feel the same as anybody else does.

Both Danielle and Kate were in agreement that 'passing' would be a useful strategy, at least in the early stages of a 'cyberspace' relationship:

Danielle

It's not a thing I think disabled people will mention first thing in an e-mail. I think they will want to get the ground work there first and then maybe mention after a couple of e-mails or whatever 'oh, by the way I'm disabled'. It's not a badge that you wear you know - 'oh, by the way my names such and such and I'm disabled'... And I think that helps. The Internet does help.

Kate

You see the real person, you don't get sidetracked by all the other things. So I wouldn't mention it unless I felt it was relevant. Yeah - people do react to you differently. Definitely.

Some commentators have suggested however that online communication is little different from offline in terms of prejudicial attitudes and stereotyping. In a recent study of 'race' and CMC for example, it was suggested that 'race' is 'no less relevant in online interaction than it is in face-to-face interaction. Instead racial stereotypes may be more influential and resilient' (Burkhalter 1999: 74). Similarly, Tim Jordan (1999) documents cases of 'cyberrape' and harassment in chatrooms, things more commonly experienced by women. He suggests that this behaviour is underpinned by identity fluidity, which provides new possibilities for harassment online. Hence writers like Liz Sayce (2000: 41) express concerns that the Internet could 'provide ever more space where there are no constraints on the expression of bigotry'. Whilst an examination of interactions in cyberspace was beyond the scope of this project, it certainly merits further study by those taking a 'social model' perspective.

Communication encompasses more than just interpersonal interactions. Disabled people have long been denied a 'voice' (Zola 1994), and IT and CMC offer the potential for them to have a creative, a cultural and a political 'voice' and to organise

collectively to improve their world. The remainder of this chapter will draw on the experiences of the fieldwork participants to critically examine this potential.

'WOW - I'VE GOT A VOICE!

Imagine not speaking for a day; imagine not being able to speak for weeks or months. Imagine the frustration you would feel if you could not communicate what you want or give your opinion on something. (Ford 2000: 6)

Jean-Dominique Bauby, ex-editor-in-chief of French Vogue, was able to dictate a best selling book following a stroke which left him with movement in just one eyelid (Bauby 1997). Less eminent people's post-stroke experiences are very different. Nancy had a stroke approximately eleven years prior to our interview, following a 'thyroid operation that went wrong'. She described how access to a computer might have helped her at that time, since she was left with no means to communicate:

Nancy

When I first 'ad this stroke I couldn't talk. Now... if they'd of been [around] then, I maybe would have communicated you know. But where it was, I 'ad speech therapy and all that and gradually got back. But that would 'ave been nice at t' time, to 'ave been able to talk to people, to tell 'em what I wanted. Because it was awful frustrating not being able to tell them what you want or what you wanted to do... I mean, you can hear what people are saying to do it.

Maude

Oh yes, you can. But you can't always speak.

Nancy

But I mean, like me it were all t' left 'and side. You've still got this right 'and to...[work a keyboard]. Oh yeah. I think they'll be a good thing for t' disabled.

There was a lot of agreement:

Helen

When you think of how many disabled people use electronic or whatever devices to communicate now, who it would have been assumed even fifty years ago or less than that, that those people had no capacity for communication you know. It's so important.

It is important. Whilst such communication aids are not the focus of this study, they do merit a brief discussion. I was shocked to meet several people during the course of the fieldwork who could not speak, yet had no such equipment, nor any other means of communication, often just relying on nods to show agreement. One woman had apparently had a communication aid which broke and was not replaced. Marc, a wizard at chess, communicated with a 'low-tech' homemade letter board. Only John had a 'high-tech' communication aid with a built-in voice and screen. He requested his Lightwriter from his social worker having been impressed by a television programme about its developer (who himself has no speech). Had he not taken this initiative, presumably he would still be using his old letter board. This might also be true had he had a different postcode. A recent report highlighting the piecemeal and inadequate provision of such communication aids concludes that 'Speech-impaired people are being denied their fundamental human right to communicate for want of an efficient and properly resourced service' (Ford 2000: 6). The technology is there. It is not reaching those who need it. This must be changed as a matter of urgency.

Those without speech are not the only disabled people to be 'without a voice', or a means to express themselves. Here too it seems that technology can help - at least in some cases. Illich's concept of 'convivial tools' is used to describe those tools which 'give each person who uses them the greatest opportunity to enrich the environment with the fruits of his or her vision' (Illich 1973: 21). Kate's initial experience of IT was not as a convivial tool however. She has a degree in Fine Art and her initial interest in IT was prompted by increasing dexterity problems which were making drawing difficult. Whilst she feels she has gained much through her involvement with the COL project, she is still unable to express herself through her drawing:

Kate

With my computer they've given me, rather than a normal mouse, which I find quite difficult, I've got... a pen which potentially you could use for drawing, but I find it very difficult to use... I've heard somebody just call it ... blankets and quilts. It's to do with a little leap of logic. Everybody used to just have blankets and when somebody said 'well why don't we have quilts, like duvets?'... you couldn't get your mind round thinking about it because it was like a whole new concept. And I think I've maybe got to come to the drawing with the computer like that, sort of think 'well, I can't do it in the same way that I used to before, but I'll have to learn how to be creative with the computer instead'... I don't think I've done it yet. I think I tried really, really hard with this particular drawing package and I think it was the wrong one... I think I was so discouraged by putting all this time into [it], I think part of my brain sort of said 'well you can't do it with a computer'. But I think I need to give it another chance and try it again.

The computer has however enabled her to express herself through writing again, which has had a major effect on her self-confidence:

Kate

It's opened up me being able to keep in communication with other people. I've been able to write. When it came to important letters I would leave [my husband] to write them, whereas I can tackle them now. So that gave me some sort of self-confidence again... And also because of the dexterity... as I'm like composing it in my mind, the actual writing something and crossing something out, and writing it again was just too much. Whereas I can play about on the computer. I feel I can express myself. My personality comes out a bit more because I can have fun writing the letters.

If more disabled people are enabled to communicate through technology, they will inevitably begin to communicate their dissatisfaction with their world. They might find creative ways to express this dissatisfaction through various cultural

forms. This process may have a 'liberatory effect on people, encouraging them to change from being passive and dependent to being creative and active' (Morrison and Finkelstein 1993: 127). Several participants in the COL project were using their computers in a creative way, and finding a growing sense of empowerment through so doing. COL produced two newsletters before its demise. Kate was involved in their editing, a process she gained a great deal from:

Kate

I think sometimes with disability and restrictions, you begin to feel that you're not useful to anybody, because you haven't got a job... and suddenly there were avenues within the City-on-Line project where you sort of think 'wow - I've got a voice!' And it seemed significant... what I have to say bears a relevance to somebody. That felt really good.

Several other COL participants contributed work to the newsletters, Bill included. Despite reservations, Bill says he 'did go forward in a way' through his involvement with the project. He started to write poetry. He claims this is something he would never have done without the computer. As he explained, his poetry communicates his deep dissatisfaction with disabled people's place in society:

Bill

It were just the way that I felt... wound up, pissed off like, with meself - life! And I felt better you know getting it out in words. I mean I can write but it's all over t' place. So when I got t' printer with t' computer... I did them poems on that computer. But really strong poems... What I'm getting at in me poetry is like the medical model, stuff like that. Like 'we'll spend fifty million on a new drug to cure you' - like a magic wand sort of thing - and that's for a year. And then they haven't got this magic wand in a year, so they spend another fifty million, where they could be spending them fifty millions on improving access to make life worth living. I mean that's more realistic than a magic wand or a magic drug or whatever you want to call it... That's the way I look at life.

It would, at this point, have been wonderful to include one of Bill's poems. For reasons of anonymity, I have decided against doing so.

Martyn writes stories: 'I've written two novels, over a hundred short stories, and I'm on my third novel. I'm trying to get published but nobody's interested [laughter]'. He delighted his fellow COL participants (and me), by regularly e-mailing us short stories. His story writing came about through his use of computers: 'I don't know where they were coming from. I was typing away and the stories were coming out'. He has also developed an impressive web site. Whilst his stories do not have the same political content as Bill's poetry, they still give him an opportunity to express himself creatively as a disabled person. Both Curtis and John also write stories, some of which were reproduced in the COL newsletter. Neither of them would be able to express themselves in this way without the aid of IT. Some, like Edith, found their equipment less 'convivial' however:

Edith

Well I was hoping I'd write - write my life story. That's what it's for. And I press a button, nothing comes on the screen! Nothing whatever... I was going 'oh I'll do marvellous! Start writing from the beginning of my life and tell me story' [laughter] ... I can't spell very well I know that. I got the dictionary out. I was gonna have fun. I was gonna have the time of my life! But no, I didn't.

Everyone I spoke to who had been involved with the project, in spite of the many criticisms they had, felt lucky to have been selected. Some however expressed concerns about being given what so many of their peers would have:

Kate

I still have a little bit of the moral issue with the City-on-Line project and the computer I have. Just like I said - 'some people are more equal than others'. Yeah, I feel I've been really privileged to be involved in it and to have had that opportunity. And I sort of think disabled people just lose their confidence and lose their self worth so much, and I think it gives you some of that back. And I sort of think 'wow' - to

actually give some disabled people that feeling of worth and that they actually do have a voice and their voice is important and worthwhile. I think that makes it more essential for a disabled person than a non-disabled person because they're already disadvantaged socially.

If current trends continue, it will be the privileged few amongst the disabled community who gain a 'voice' through the use of ICT to communicate their anger, aspirations and creativity. It is important to remember though that cultural involvement will not necessarily lead to collective emancipation. As Starr (2000: 36) reminds us: 'while culture plays important roles, it was never the only medium of, for example, slave rebellions'. Disabled people need social transformation, not simply the means to express themselves culturally. Can communication systems facilitate such transformations? This question will be debated below.

DISABLED PEOPLE AND E-ACTIVISM

One of the wonderful things about the interactive network is that virtual equity can be achieved much more easily than real-world equity... We are all created equal in the virtual world, and we can use this equality to help address some of the sociological problems that society has yet to solve in the physical world... The network won't eliminate barriers of inequality and prejudice, but it will be a powerful force in that direction. (Gates 1996: 294)

The above quotation is typical of much of the current rhetoric about the liberatory potential of the Internet. As one commentator reminds us, a large proportion of Internet theorists and activists are free market libertarians, and as such tend to ignore the social contexts in which online activity occurs, or treat 'the latter as a panacea for the problems of the former' (Fitzpatrick 2000: 379). Others question whether online sociability will ever translate into political solidarity and thus lead to political and social change (Breslow 1997).

Despite these concerns however, it is suggested that cyberspace may be not only an instrument of association and dissemination, but also of mobilisation. Hence, it is

argued that one of the main potentials offered by use of the Internet is its ability to advance the 'the interests of politically and socially disadvantaged groups' (Fitzpatrick 2000: 386). This is a theme carried through in the disability studies literature. Liz Johnson and Eileen Moxon (1998: 254-255) make the following claims for example:

That a global movement of disabled people has now developed into a significant political force is thanks in no small measure to the wonders of communication and information technologies...*The rapid growth of a world-wide disability movement is in itself evidence of the part which new technologies can play in facilitating the empowerment of disabled people.*

However, the proof for such claims remains elusive. It is a difficult, if not impossible task to 'predict the effects of online communication for collective action conducted by disempowered groups' (Mele 1999: 306) and as yet, for disabled people, little more than prediction is open to us.

It is easy to find examples of disabled people coming together on the Internet to discuss for example disability research (disabilityresearch@mailbase.com), or disability politics and direct action (danmail@egroups.com). An activist friend tells me she now spends around an hour and a half every evening on such discussion lists, and it is likely that such participation has an empowering effect on many disabled individuals who might otherwise be starved of such interaction. The implications for the disabled community as a whole are more debatable. As a recent *Coalition* article asks:

What with Disabilitynet, DANMAIL, Disability-research and all the other e-mail lists around these days, have disabled people disappeared into the phone lines to discuss issues and share support? If so, although this can be brilliant for those of us who have access to e-mail, the exclusion of other disabled people is worrying. (Cunningham 2000: 11)

This exclusion is indeed worrying. As yet these discussion lists are mainly confined to a privileged few, posting messages from Europe and North America. There is little evidence of true global exchange between those in the minority world, and those in the majority world, and many disabled people living in the minority world are also

excluded. As Rachel Hurst from Disability Awareness in Action (DAA) suggests, the Internet in effect reinforces the differences between disabled people. Hence, whilst DAA has an 'e-group', disabled people's organisations from the majority world are not part of it (Hurst 2000).

There are however a wealth of 'intentional communities' operating online - 'people coming together for a common purpose' - and a new 'wired' political community is said to be emerging (Walch 1999: 17). The 'enemy' for these emerging social movements is frequently global capitalism (Starr 2000). Hence, the Internet is said to have played a major role in mobilising the demonstrators at recent anti-capitalist protests in Prague, Seattle and so on (Cassell 2000; Grosvenor 2000). The Zapatista movement in Chiapas, Mexico is also held up as an example of a group whose struggle has been aided by electronic communication (Castells 1997; Walch 1999). However, far from representing the '*first informational guerrilla movement*' (Castells 1997: 79) as many suggest, most of the net postings raising awareness of the Zapatista cause were sent not from Mexico, but from the United States and Europe (Froehling 1999). The hype suggests that the Zapatistas are directly communicating with the world. There is however extreme material deprivation in the area of the uprising, 'which includes an absence of roads, electricity, telephone and communications in general' (Froehling 1999: 171). In effect then, the real story is of a

more or less co-ordinated effort of supporters in different places, with different agendas (churches, human rights groups, left political groups) that converge around the issue of the Zapatista uprising. Cyberzapatistas are everywhere but they are not controlled by the Zapatistas in Chiapas. (Froehling 1999: 171)

Oliver Froehling (1999: 172) suggests that the Zapatista cause has similarities with that of the Internet community 'that sees itself threatened through government regulation and commercialisation'. Hence the Zapatistas struck a chord with 'Internet aficionados' and gained their support. This is arguably the case too with the recent protest in Prague against the International Monetary Fund (IMF) and the World Bank. It seems this may also apply to the struggle for disabled people's liberation. Liz Sayce (2000) highlights how the libertarian campaign against forced treatment for

psychiatric system users/survivors has achieved some success in the United States through the use of Internet lobbying. As described previously, libertarian ideas flourish amongst Internet activists, and therefore commonality is again present. Until such time as disabled people everywhere are connected to the Internet - a time which may never come - at best it seems that those privileged disabled people who are connected will dominate the political agenda in cyberspace. At worst, as with the Zapatistas, the cause of disabled people may be appropriated by non-disabled people to further their own agendas. It is suggested that the 'very act of connecting to other like minded people on the other side of the world to bring about social change is in itself of symbolic and political importance' (Walch 1999: 146). How far any of this networking will translate into material gains in the real world remains to be seen however. Whilst many disabled individuals are undoubtedly politicising themselves and finding empowerment through online discussions with like-minded people, the question remains: 'will better-honed arguments mean more effective activism?' (Mort 1999: 2). Whilst it may be possible to change a few people's minds, 'changing minds does not change reality; it still needs people to make a revolution' (Sivanandan 1997: 295). The Internet's success as a political tool cannot then be measured by the number of web sites or discussion lists. Instead, we must look to 'the multiple effects produced in other spaces outside cyberspace' (Froehling 1999: 176). If and how these 'multiple effects' will be manifested remains to be seen.

It was suggested almost forty years ago that 'perhaps precisely because violence and power seeking are not really practical possibilities for us, we are well placed to consider other ways of achieving freedom from injustice' (Hunt 1966: 155). Neil Small and Penny Rhodes (2000: 89) echo these concerns and suggest electronic networking as a possible solution:

Although people who are seriously ill may not be able to take part in conventional forms of direct action such as demonstrations, electronic communication gives them the ability to network quickly and cheaply and provides the potential for direct action

It is vital for activists within the disabled people's movement to use any means at their disposal to make a better world, and perhaps the Internet could become an important tool in this process.

Disabled people are beginning to find innovative ways to challenge their oppression with the aid of Internet technology. Disabled artist and activist Paul Darke for example targeted charity, specifically Leonard Cheshire: 'the leading charity provider of services for disabled people in the UK today' (Carr 2000: 29). He purchased the domain name www.leonard-cheshire.com, for just £25, and created a web site which highlighted the organisation's oppressive practices. As an ironic gesture, he put the site up for auction at £46,000 to fund a disabled people's holocaust memorial:

There was no way anyone was ever gonna pay any money for it whatsoever. It was just about taking the piss about fundraising, about how charities do raise money for things they believe in, that obviously are about furthering the disempowerment of disabled people by the processes of charity - making disabled people victims of impairment as opposed to victims of society - which is what the holocaust memorial was about. (Darke 2001)

The site received 51,000 hits before Leonard Cheshire, with the assistance of WIPO, successfully closed it down (see Chapter Seven). As Darke suggests then:

The web isn't this free for all, this radical free for all of anarchism that people think it is. It is a very controlled and defined space that you can only survive as a radical in for a very short period of time before you are marginalised within it, just like you are within society, just like you are in the mainstream media... You can get your short sharp shock, but it is very short and sharp before you lose.

He is not deterred however. With the assistance of other disabled people he has purchased more domain names which are similar to that used by Leonard Cheshire (www.leonard-cheshire.org) and plans to get the site up and running again. He is keen that others follow suit:

there's still loads of domain names out there for individuals to buy about their charities that are abusing their impairment group... It's as easy as word

processing... If you get the right software package it does it all for you, there's no programming or anything.

He is however under few illusions about the 'real world' effects of such action. Leonard Cheshire, he predicts 'will quietly brush this aside, and they will go from strength to strength'. What though of other radical tactics that can be employed by disabled activists?

Hacking - 'unauthorised computer intrusion' (Jordan and Taylor 1998: 757) - is becoming a credible activity for activists. Targets are hit with 'electronic weapons' like viruses and e-mail bombs (which crash web sites by bombarding them with protest messages). Salford University's Paul Taylor describes such activities as 'the latest manifestation of a long history of opposition to capitalism and its disorienting effects' (Millar 2001: 4). The UK government has recently passed draconian legislation which makes many forms of e-activism, 'hacktivism' or 'cyber-terrorism' unlawful. As former foreign secretary Robin Cook has warned: 'hacking could cripple Britain faster than a military strike because computers are managing most of the country's infrastructure' (Hopkins 2001: 1). The Internet then has the potential not just to facilitate networking, but also to bring the country to its knees. Martyn highlighted how,

Martyn

A computer can be a lethal weapon in the wrong hands... I can get into Edith's computer, if I wanted to, and I could wipe all her e-mail out. I could really mess her up and she wouldn't know it was me. I could get into databases and create havoc by using a false e-mail address. Now - that is dangerous. It's illegal. I would never do it and I'm saying that for the tape. I would never do it, but it's possible. It is a lethal weapon. Businesses can be wiped out. So you give a computer and it's in the wrong hands, somebody's that way inclined, it's like giving them a rifle.

Perhaps then a computer could also be a useful weapon in the *right* hands. Organisations such as the Electrohippies Collective (2001: 1) are leading the way in developing the Internet as a 'viable means for public dissent, debate and protest —

mirroring the traditional means of political and social expression that exist in everyday society'. The disabled people's movement must begin to engage with these issues. As a disabled woman activist involved in one online discussion group, suggests:

We should take advantage of the Internet. I think this is a frighteningly powerful tool for fast and low effort action, which could have a huge impact if we were using it to its full advantage... I think we are still developing ideas how to use the Internet as an activist tool and maybe we should share this more as a concept. (Cunningham 2000: 12)

SUMMARY

Disabled people have long been excluded from their communities, and despite moves towards de-institutionalisation, this exclusion continues in the twenty first century. The isolation that many experience then is a deep cause for concern, having very real effects on many disabled people's quality of life. Whilst this isolation is often alleviated through use of communication systems, particularly the telephone, many disabled people are, through no fault of their own, unable to take full advantage of the contact that the telephone may offer to others. There are also concerns that mediated communication can never take the place of face-to-face interaction, and that an over-reliance on such means of affiliation may produce further isolation.

CMC offers not only the potential to talk to absent friends, but also to make new ones. As such it can widen people's social networks, and contribute to a sense of community membership. Communities inevitably exclude however, and this is no less true of cyber-communities, where prejudice and exclusion also thrive. Prejudice can to an extent be avoided in Internet interactions through strategies of non-disclosure. Thus, it seems that any sense of community membership is often dependent on the adoption of a non-disabled identity.

Most importantly perhaps, CMC can also facilitate communication between disabled people, providing peer support and cultural and political empowerment for

those who are able to 'log on'. Whilst the effects of such online interaction for political progress in the material world merit further investigation, it seems likely that the Internet may become an important tool for those 'connected' disabled people who are involved in grass roots activism. Perhaps it is here that the use-value of communication systems for disabled people will prove most potent in the twenty first century.

CHAPTER NINE: TOWARD A BRAVE NEW WORLD?

The main strands of this thesis concerned disabled people's continuing struggles for emancipation, and the implications of communications systems for facilitating such change. These issues were addressed through a study of access to such technology, and its perceived use-value. In conclusion, it seems appropriate to revisit these key themes. A brief summary and discussion of findings will therefore be presented. Recommendations will then be made which may ensure that communication systems are used to assist rather than hinder us. Finally the limitations of such reforms will be briefly considered.

SUMMARY OF FINDINGS

The fieldwork demonstrated that easy access to communication systems, whilst considered vital, is still a major problem. Both corporations and governments are culpable. Corporations now wield an immense amount of power, and their manifest functions of 'helping' disabled and older people are secondary to their latent function of profit making. Despite organisational rhetoric to the contrary, disabled people are not designed in to products from the outset, and provision of essential product information takes a low priority. OFTEL in its role as regulator, does not appear to have either the power or the will to improve the situation. Hence disabled people are often unable to use even basic telephone equipment to their advantage. The situation is even more critical for those wishing to access newer innovations such as mobile telephony and IT.

Disabled people are no longer completely invisible, and are increasingly being recognised as an exploitable market. Whilst this might be seen as a step forward, disabled people seem suspicious. Many lack the resources to 'buy in'. There is also a possibility that this new recognition could provide mechanisms for the creation of

'false needs' and thereby exacerbate poverty levels. Commitments to universal design principles, user involvement and widespread information provision may have some benefits in the future. We cannot however expect market forces to guarantee access for a relatively small social grouping with little disposable income. The state then must take some responsibility. Through appropriate legislation it could require manufacturers to make accessible products, and thus enshrine disabled people's rights to communication systems in the law. This may be difficult to enforce at a national level, suggesting the additional need for an international organisation with access to communication systems as its remit. This must not distract us into denying the socio-structural origins of the problem however.

The physical accessibility of communication systems is only the tip of the iceberg. It is just one consequence of disabled people's continuing oppression, along with poverty, inadequate and inaccessible education, low self-esteem, and a variety of other disabling barriers. Of these, poverty looms largest. With the majority of disabled people still excluded from the labour market through disablist and ageist practices, the continuing erosion of the welfare safety net is a particular concern in the twenty first century. This trend could be arrested were there a political will to do so.

The state could also play a useful part by developing new means to provide disabled people with necessary communication systems. Pilot projects such as COL cannot be the way forward for the disabled population. A more strategic approach is necessary. This must be formulated in partnership with disabled people and their organisations. Whilst the recycling of old computers has been suggested by the government, this is not universally popular and would inevitably leave disabled people lagging behind. The provision of IT in communal venues was sometimes raised as a solution, but problems such as inaccessible transport and lack of access to the built environment could make this problematic for disabled people, and some would rather have access at home. The introduction of a comprehensive disability income was also suggested by participants as a means of affording essential communication systems. I proposed that DLA could perhaps include a communication component alongside the existing 'care' and mobility components.

This would enable the acquisition not only of computers, but also of mobile phones, and other devices, but would need to be sufficiently flexible to accommodate new and unforeseen innovations. The CSDPA could also be modified to accommodate the rapid pace of technological change. The fact remains however that such 'special' legislative moves would not be necessary were disabled people not oppressed. The removal of this disadvantage is our most pressing need.

Access to communication systems is most often linked to reformist conceptions of equality of opportunity. If non-disabled people are accessing computers and communication systems why shouldn't people who are disabled do the same? Although perhaps expedient in the short term, this may not be the most productive way forward. Equality of opportunity is not the same as equality of outcome. Disabled people also need to challenge the structures that create disability and other forms of oppression (Sheldon 1999). We may not create a more inclusive society by calling for accessible technology, we may simply move the goalposts.

Access to communication systems though regarded as increasingly necessary, was not considered the highest priority for disabled people. Most considered the removal of more traditional disabling barriers to have greater urgency. This created concern amongst many that technology might be provided as a cost cutting exercise, reducing the need to make more meaningful social changes. There is a very real danger that disabled people could be further disadvantaged through such technical fixes, finding themselves more isolated than before, and less capable of satisfying their needs in other ways. It is clear then that communication systems must never be pushed onto people as a sticking plaster solution to deeper social problems. It is also clear that the widespread, ageist and disablist concerns about apocalyptic demography could make this happen.

Whilst our oppression makes much technology inaccessible, even accessible technology can be deployed in oppressive ways. Disabled people are however finding a number of use-values in modern communication systems. This is not however to say that the needs they satisfy could not be met in non-technological ways. The most commonly cited use value of the telephone was in satisfying the need for security and the avoidance of harm. This was considered vital, especially for older people, lone

householders, and those with constraints imposed on their mobility. Community alarms were also described as a boon, allowing disabled people to continue living safely and autonomously in the community. It was proposed however that the potential of such schemes was not being realised because disabled people's unmet needs were largely secondary to those of the providers of the service. This suggests a further risk that they may be deployed at the expense of relatively costly human support, thus isolating disabled people further. The potential for disabling surveillance is also ever present, as is the danger of mechanical breakdown. The same could be argued of the new smart home technologies which have amazing potential if developed and provided in accordance with disabled people's wishes.

The Internet was being used by several participants to access information and order groceries. Participants were excited about the potential for information provision, and were using the technology to access both disability information and, more often, general leisure information. Surfing the net then is often an important leisure activity for people whose opportunities for leisure are seriously curtailed. Whilst the Internet could be a useful place to disseminate disability information, it must be disabled people and their organisations who control the flow of that information. It is also important to continue to supply information in non-electronic forms. Whilst there is still a need for information about how to live in an oppressive society, our organisations must receive more funding to provide this information. Discriminatory web design is still a major problem which, like discriminatory equipment design, must be tackled at both national and international levels. The growing power of international regulatory bodies such as WIPO could mean however that our information increasingly begins to be censored.

It was around online shopping that concerns about a technical fix were most apparent. Whilst many were pleased to be able to avoid the difficulties which shopping presented, others saw shopping as an important leisure activity and a welcome opportunity to meet people. With the impetus gone to make shops, the built environment and transport systems accessible, many feared increased isolation, further segregation, and less freedom of choice. Part three of the DDA could be more rigorously enforced in order to avoid such a technical fix.

The most exciting and innovative uses to which the Internet was being put were in the area of interpersonal communication. Disabled people are finding new ways of reducing their isolation, meeting people and expressing themselves culturally and politically. They are developing new means of expressing their anger and dissatisfaction with the world which continues to exclude them. If these online activities can translate to real world changes, then communication systems may hold the ultimate use-value - the satisfaction of the need for liberation.

However, it is always necessary to revisit our first theme - access. Unless things change, there will inevitably be disabled people who cannot access the necessary technology, as well as those who can. The same goes for the non-disabled population. In the technological society of the twenty first century 'if one is unable to pay or to operate effectively within the system, then social Darwinism takes its course and one joins the underclass' (Martin 1995: 14). Could it be this new underclass which is the disabled category of the future?

DISCUSSION

Technology is undoubtedly a two-edged sword. We have seen that disabled people are disadvantaged in many areas of their lives, that even their most basic needs remain unmet, and that their exclusion from communication systems is yet one more symptom of their oppression. We have seen that technology is not neutral, it is shaped by the same social forces which turn those with impairments into disabled people. Hence whilst current social and economic conditions prevail, communication systems may well have oppressive consequences for disabled people: reduced autonomy, dependency on often unreliable machinery and decreased levels of social contact, increased surveillance and infantilization. The increasing primacy of such systems may also reduce opportunities to satisfy basic needs by other means, thus imposing radical monopoly, enforcing compulsory consumption of technological commodities, and increasing levels of income disparity. This will inevitably lead to polarisation within the current 'disabled' category.

Communication systems can also have enormous use-value for disabled people, enabling many of their unmet needs to be fulfilled. The technology can allow disabled people to feel safe in their own homes and on the street, remove the necessity for support from sometimes unreliable strangers, facilitate information provision and sharing, reduce the difficulties of purchasing consumer staples and the need to face a hostile outside world, decrease boredom, allow new means of cultural expression, provide opportunities to meet and communicate with like minded people, and facilitate new forms of oppositional politics and direct action.

Undeniably, we have come a long way. The technology that is available to those with means *is* amazing, and there is little to suggest that its development will not continue to startle us. Whether its development will accompany any kind of social 'progress' is more debatable however. Many of those who might benefit from these extraordinary scientific 'miracles' will probably never have the opportunity to exploit them. We live in a society where even low-tech devices such as ramps and electronic doors are not widely available. Why then would we assume that that society would distribute its twenty first century technological goods in an equitable way? As Castells (2000: 390) suggests

The dream of the Enlightenment, that science and reason would solve the problems of humankind is within reach. Yet there is an extraordinary gap between our technological overdevelopment and our social underdevelopment.

It is this social underdevelopment that will hold disabled people back in the twenty first century. This is surely where change must be focussed.

The key to developing socially responsible technology is indeed who controls the process and practice of technological innovation. Disabled people's unmet needs are not generally placed centre stage in the research and development process, but rather the needs of professional technologists and service providers. Whilst technology continues to be hailed as the answer to the assumed problems of apocalyptic demography and disability as personal tragedy, the wrong questions are being asked. In the short term, the following recommendations might go some way toward

improving this situation. They involve action at global, national and grass roots levels:

RECOMMENDATIONS

1. Disabled people must be enabled to create their own use-values, through their involvement at every stage of the innovation process.
2. Corporations must become more accountable and universal design principles enforced more rigorously. Whilst the British government could play a role, this would probably be best achieved through international intervention. A UN body with access to communication systems as their remit could police both the accessibility of equipment, and the design of web sites. Where specialist design is still deemed necessary, the idea of a universal pricing structure must be re-examined
3. There is an urgent need for strategic planning around disability and technology. State and European Union funding should be channelled into such activities rather than the endless stream of ill conceived and poorly executed pilot projects. This planning *must* include disabled people and their organisations at all stages, and it must proceed with full awareness of the multitude of non-technological barriers that continue to exclude us. We must avoid oppressive technical fixes.
4. Technology must not be offered as a solution to what are social or economic problems, or disabled people's autonomy will be further impaired. Neither must it be forced onto disabled people as a cheap substitute for human support. Efforts to eradicate pre-existing disabling barriers must be stepped up to avoid the dangers of such technical fixes.
5. Disabled people must be enabled to access any technology that could benefit them, without being forced to pay more than their non-disabled counterparts. This must occur irrespective of their educational or occupational status. This could occur through the extension and improvement of legislation such as the CSDPA

to cover all forms of information and communication systems, or the extension of DLA to include a third component - communication.

6. We must make ageism a thing of the past. Older people's vital contributions must be valued, and age-discrimination in employment and service provision made unlawful. Whilst recognising that similar legislation for women, black people and disabled people has not eradicated the disadvantage faced by these groups, such legislation would at the very least demonstrate a willingness to recognise the problems of ageing as problems not of biology, but of society.
7. Disabled people and their organisations must continue to support those disabled people who are 'information poor', since this may become a significant dimension of oppression in the twenty-first century.
8. An independent organisation run by and for disabled people must be established as a matter of urgency. This organisation would provide information, training and support to disabled people interested in utilising ICTs. It would also contribute to debates about the future direction of communication systems.
9. Disabled people and their organisations must continue to find *innovative means of collaboration, peer support, consciousness raising and dissent*. Their attempts to influence real world politics must be stepped up both through *traditional means of protest, and new forms of e-activism*.

THE LIMITS OF REFORM

Enactment of the above recommendations would go some way towards creating a future in which the double-edged sword of technology does not carve out further disadvantage for disabled people. It would alleviate certain symptoms of our oppression. It is important however to recognise the limitations of such reform. The implementation of the above recommendations will not remove that oppression at its source. For this to occur more radical change will still be necessary. Since capitalist society is implicated in the oppression of disabled people and other oppressed groups,

in order to remove this oppression, we need 'a *radical transformation*, rather than a reform of capitalism' (Gleeson 1997: 196).

The new technologies are developed within the capitalist system, and are now enabling capitalism to spread its reach on a global scale. Whilst capitalism continues to dominate the world stage, it seems likely that technological development, built in obsolescence, and compulsory consumption will result in increased polarisation both between and within societies. As some Marxist commentators suggest:

We enthusiastically welcome the promise of technology for ending material scarcity and for creating a foundation for higher forms of human fulfilment. Yet we suspect that the application of electronic technology within capitalism will not only fail to meet these ends, but exacerbate the misery and poverty in which most of the world already lives. (Davis et al. 1997: 3)

It seems that whilst certain disabled people might find themselves in a better position thanks to communication systems, there will be many more who will not benefit. Older disabled people may well be particularly vulnerable to this exclusion, as may disabled women. The new technology's emphasis on 'intellectual capital' could well exclude those with learning difficulties or those with impairments that create difficulties with concentration or memory. Those who lack the necessary energy to learn to utilise the systems will also be disadvantaged. Even those non-disabled people who 'just do not get on with computers' might find themselves pathologised, and forced into the ranks with disabled people. Perhaps then we will begin to see new classes, and a new kind of 'disabled' category emerging. Whilst this might be liberating for some currently disabled people, those disabled by the society of the future will not be so enthusiastic.

What we need most then is to transform society - the society that created the Internet, the society that oppresses. A truly inclusive future must recognise that technology is not a panacea. It must reject the technological and biological determinism that underpins both the disablement of impaired people, and the uncritical belief in the 'technological Second Coming' (Mills 1959: 168). It must ensure that society delivers its bounties in an equitable manner. Finally it must allow disabled people the liberty to create their own use-values, and shape their future as

they see fit. Radical changes will be necessary before this wish list will be met, but we *have* to believe that such change is possible, that we *can* make our own history.

The technological 'development' programme embraced by corporations and politicians alike is happening outside of the democratic process. Nobody has been consulted. We are all encouraged to uncritically accept the imposition of these new needs. Little wonder then that disabled people, older people, women and those from other oppressed groups are being sidelined. It is in all our interests to change this way of working. One of the few means of resistance in a non-democratic technological world, is a refusal to consume its products. This great refusal however becomes increasingly untenable in a society where communication systems are gradually monopolising the satisfaction of even our most basic human needs. None of us are free, and some are less free than others. Disabled people and those from other oppressed groups are possibly in the best position to recognise this. For Marcuse (1964: 199-200), the new agents of change are 'the substratum of the outcasts and the outsiders, the exploited and persecuted of other races and other colours, the unemployed and the unemployable'. Perhaps then we can lead the way in formulating alternatives.

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