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USER INVOLVEMENT IN
COMMUNITY CARE POLICIES:
DOES IT FULFIL OR DISSIPATE THE VISION
OF DISABILITY RIGHTS CAMPAIGNERS?

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Abstract

One focus of the early disability rights movement in the sixties and seventies was to demand a voice for disabled people in the formation of policy that affects their lives - "nothing about us, without us". Policy makers are now required to take into account the views of users: do current methods of user involvement fulfil or dissipate the vision of disability rights campaigners?

To the casual observer, it may seem that this struggle was successful, as recent legislation like the Community Care (Direct Payments) Act 1996 and the Care Standards Act 2000 incorporate the requirement for service providers to consult with users and to design services around individuals' needs: thousands of disabled people are now participating in a range of UI exercises.

However, UI tends to draw disabled people into partnerships with service providers, and some activists are concerned that disability organisations are becoming enmeshed in "the very system they were developed to oppose."

If what appears to be an advance has the potential to become distorted, further segregate or work against the empowerment of disabled people, it is important that we address the issue of whether UI is in practice a means by which service providers are being challenged "to take account of us, to listen to what we have to say". To this end, the aims of this research project are to evaluate disabled people's experiences of being involved in research and consultation projects, and to assess (from disabled people's perspective), the impact of recent user involvement

practices by identifying tangible signs of change. The focus of this study is on UI relating to the services provided primarily by statutory agencies such as health and social services.

This study provides a background to UI by reference to a wider body of research and recent policy developments, as well as presenting a snapshot of the current picture by means of two small-scale pieces of fieldwork.

To address the question of UI's efficacy as a means of gathering and communicating disabled people's perspective, a small number of interviews were carried out with participants in two recent studies. To assess whether UI is delivering positive outcomes for disabled people, a survey was undertaken with a sample group of organisations controlled by disabled people focusing on projects completed over the last five years.

Participants' views of UI exercises were largely positive. Many pointed to benefits in terms of personal and corporate empowerment. The overwhelming weight of opinion is that UI is a worthwhile activity when properly conducted, despite the relative paucity of tangible changes to service provision.

Lack of concrete benefits contributed to some disillusionment and feelings of being 'used' by professionals with their own agenda. There was also a considerable degree of consultation fatigue and a perception that there is too much UI, which distracts organisations from other activities, particularly as UI exercises tend to attract funding. Individuals

and organisations are becoming more selective when they decide whether to participate in UI.

In conclusion, UI is seen by most as a positive development, especially where genuine partnerships are forged with service providers. However, there are still attitudinal barriers to break down, and there is very little UI activity with agencies other than social services. Indeed, disability organisations often depend for a large part of their budget on local authority funding of UI activities, and this must have an effect on their independence and ability to campaign effectively at a local level. This study calls for thought to be given to alternative means of funding citizen participation and to creating a situation of equal partnership between providers and users.

"Nowadays many disabled people will have nothing to do with resignation as it used to be understood. Thriving in a climate of increasing public tolerance and kindness, and on a diet of pensions and welfare, we are becoming presumptuous. Now we reject any views of ourselves as being lucky to be allowed to live . . . we are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part of society itself." (Hunt, 1966:9)

One focus of the early disability rights movement in the sixties and seventies was to demand a voice for disabled people in the formation of policy that affects their lives - "nothing about us, without us". Policy makers are now required to take into account the views of users: do current methods of user involvement fulfil or dissipate the vision of disability rights campaigners?

1.1.1.1.1 Chapter one: Introduction
1.1.1.2

This introductory chapter will outline the development of user involvement (UI), question its current status with regard to the emancipation of disabled people and set out the aims of this study.

CAMPAIGNS AND ACHIEVEMENTS

The disability rights movement in the United Kingdom was sparked off by the struggle of a group of disabled people living in institutional 'care' to get their voice heard, and so achieve the living conditions they desired. Throughout the growth of the movement in the 1970s and 80s, disabled people campaigned to be represented by their own organisations (rather

than charities or quangos) and for greater involvement in the development and management of services for disabled people (UPIAS, 1976; Ratzka, 1992; Coleridge, 1993; Barnes & Mercer, 1995). To the casual observer, it may seem that this struggle was successful, as recent legislation like the Community Care (Direct Payments) Act 1996 and the Care Standards Act 2000 incorporate the requirement for service providers to consult with users and to design services around individuals' needs.

However, even at best these legislative requirements represent a compromise with the demands of disabled campaigners, an outcome that was hardly a surprise to many analysts. In a review of the disabled people's movement and disability policy, Davis (1996, 1998) argues that from the start of disabled people's political mobilisation, it was inevitable that there would be power struggles between disabled people and those who had personal stakes in maintaining the status quo. As an example, he cites the campaign by disabled people for anti-discrimination legislation which, after over a decade of lobbying and fourteen attempts to get a law onto the statute books, resulted in the poorly drafted, functionally-based Disability Discrimination Act of 1995, which many disabled activists do not recognise due to its inadequacy. Furthermore, although the Act was eventually passed into law, this was as much a consequence of the political embarrassment caused by the revelation of machinations designed to block it (Carmichael, 1997), as it was a consequence of disabled people's struggle.

Nevertheless, despite the perceived inadequacies of the Disability Discrimination Act (1995) and subsequent legislation, during the 1990s consultation exercises did become an increasingly common element of

policy reviews affecting services for disabled people. The form taken by these exercises varied widely: for example, some involved only the occasional input required to draw up local authority (LA) Community Care Plans or that of small groups working to influence home care services, whereas others (including reviews of day care or direct payment provision) were on a much larger scale. In the past few years, some initiatives have appeared to be going further towards giving control to disabled people who are service users through the development of 'user-led' reviews or by consulting with groups previously perceived as being 'too difficult or unsuitable' to take part, like people with learning difficulties or those with communication needs.

Thus UI is now seen as an essential part of the policy making process and lends credibility to the decisions made as a result of policy review. In essence, UI has become the slot reserved for disabled people to influence decisions made within statutory and voluntary sector service provision that may have a profound effect on their lives, and thousands of disabled people are now participating in a range of UI exercises. Furthermore, as a result of the challenges put forward by disabled people regarding the conduct of social research and the power relationships that exist within it, this activity has also begun to move away from viewing disabled people merely as 'subjects' for study: a number of researchers are now either themselves disabled people or are working within Emancipatory or participatory paradigms, recognising the principles of the social model of disability.

1.1.1.3THE NEED TO BE VIGILANT

On first glance, then, it would appear that the current climate of 'listening to and involving' disabled people in all areas of service provision represents a significant move forward at both local and national levels. However, UI tends to draw disabled people into partnerships with service providers, and there are a number of potential hazards in building alliances with statutory and charitable organisations, as Hevey highlights. During the campaign for civil rights in the 1980s and 90s, he believes that the British Council of Disabled People (BCODP) too readily accepted the support offered by traditional charities, bodies which (he reminds us) have always been viewed as responsible for maintaining disabled people's oppression. To Hevey, it is obvious that self-interest was the motive behind such actions:

> "My theory is [that charities support civil rights] because if they (disabled people) get rights, then services will grow and they'll gain."
> (Hevey, in Campbell & Oliver, 1996:140)

Other disability activists highlight similar concerns:

> "What is tending to happen is our clothes are being taken off us and being used in the process of oppression. One of the things we learnt in Le Court is that actually the system has a great capacity for taking your ideas and reinterpreting them to their benefit. The whole idea of resident participation was something Paul Hunt fought for and he would be appalled to see how it's been used and manipulated, actually so as to enable the oppressor further to control the lives of disabled people." (Mason, 1996:163 cited in Campbell & Oliver, 1996)

In the United States, where the disability movement has a longer history, a growing number of disabled Americans are becoming very critical of how their organisations are ignoring grass roots constituents at a time when disabled people's rights and entitlements are being eroded by right wing politics, concentrating instead on becoming:

> "the service organisation rather than advocates. They are so tied up with funding directives that prevent them from expressing [their] views, they have become the very system they were developed to oppose."
> (Woodward, 1995)

1.1.1.4 AIMS AND OBJECTIVES OF THIS STUDY

If what appears to be an advance has the potential to become distorted, further segregate or work against the empowerment of disabled people, it is important that we address the issue of whether UI is in practice a means by which service providers are being challenged "to take account of us, to listen to what we have to say". To this end, the aims of this research project are to evaluate disabled people's experiences of being involved in research and consultation projects, and to assess (from disabled people's perspective), the impact of recent UI practices by identifying tangible signs of change.

The focus of this study will be on UI relating to the services provided primarily by statutory agencies such as health and social services, as opposed to UI in services run by disabled people, or within the wider arena of citizenship participation. The importance of these other aspects of UI is recognised, but the scope of this dissertation is necessarily limited. Furthermore, a comprehensive evaluation of services led by disabled people, including the role of users and peer support within those

organisations, has been provided by a recent two year project entitled "Creating Independent Futures" (Barnes, Morgan, Mercer, 2001). This dissertation will not attempt to provide a comprehensive list of all UI activities ever undertaken, because it is doubtful that suitable records exist; nor will it provide guidance on how to undertake consultation or related exercises, as this aspect has been well documented elsewhere. It is also not the intention of this dissertation to develop a tool or provide a benchmark for measuring UI, as other researchers are better positioned to do this. However, within the limited resources available, this dissertation will attempt to provide a snapshot of current and recent practices and consider the impact that disabled people's involvement has made at local and national levels.

To provide a background to the current status of UI, this study will, by reference to a wider body of research, examine the history of disabled people's involvement in both service provision and disability research and place it in context. It will define relevant terms and set out some examples of the different types of UI currently or recently in use. An examination will then be made of the power relationships present in UI exercises and the links with wider pressure group politics will briefly be examined.

In order to address the specific aims of the project, this study will employ the following approaches:

1. To address the question of UI's efficacy as a means of gathering and communicating disabled people's perspective, a small number of interviews with participants in two recent studies will be undertaken.

Through the analysis of their responses, this qualitative exercise will attempt to establish the value of UI in these sample sites.

2. To assess whether, within the relatively short lifetime of UI as a part of local policy making, concrete outcomes have been delivered, a quantitative postal and email survey will be undertaken with a sample group of organisations controlled by disabled people in order to gauge the impact of collective participation in a number of projects completed over the last five years.

Finally, this study will identify key issues that have emerged and present an assessment of the value of UI as a means by which disabled people as service users can effect change in policy and practice.

1.1.1.4.1 Chapter two: Literature and policy context

This chapter reviews the emergence of UI, its definition and examination by previous studies. It also looks at issues of citizenship and developments in disability research theory.

THE DISABILITY MOVEMENT AND CONSULTATION

Campaigning for a voice in service provision

Although the first stirrings of disability protest had begun in the 19th century it was not until the 1960s, according to Campbell & Oliver's account of the emergence of the movement, that disabled people started to come together collectively and to challenge the role of paternalistic impairment-specific charities like the RNID and SCOPE (formerly the Spastics Society) who, together with the growing body of welfare professionals, sought to speak on behalf of and had significant influence over the lives of disabled people.   By breaking away from the traditional charities and forming new pressure groups (Campbell & Oliver, 1996), disabled people were able to question their position in society, how they wished to be perceived and to develop the roles they would play in the wider struggle against their oppression.

However, it was an individual and his struggle to become a consumer of services and to exercise choice and control which gave a kick-start to the disability movement in the UK. Paul Hunt (a 'care' home resident and later one of the founders of the independent living movement) wrote to the Guardian newspaper in 1972 proposing:

"the formation of a consumer group to put forward nationally, the views
of actual and potential residents of these successors to the
Workhouse" (Hunt, 1972).

The formation of the Union of the Physically Impaired Against
Segregation (UPIAS) was a direct result of Hunt's letter: the politicisation
of disabled people was underway. As the movement developed, so did
the redefinition of disabled people through what has become known as
the 'social model of disability'. This model, accredited as originating from
within UPIAS (Campbell & Oliver, 1996), frames the causes of disability
in social terms rather than viewing the disabled person's pathology as
the problem: in this way disabled people can express their situation in
terms of human rights and as an issue of equality.

The British Council of Organisations of Disabled People (BCODP)
succeeded UPIAS in 1981 and, as an umbrella organisation, provided
the formal base for political campaigns by organisations *of* disabled
people (Campbell & Oliver, 1996).

One focus of the disability movement from its inception(reflected as early
as Hunt's letter) has been to establish that only disabled people can
speak for the needs of disabled people:

> "It is only the disabled person who can satisfactorily define his or her
> needs in terms of the enabling of equal opportunity. This is the basis of
> demanding consultation and it is the purpose of consultation."
> (Consumer Consultation, HCIL, 1990)

The demand for consultation proved impossible to deny during the early
1990s, in the face of determined demonstrations by groups of disabled
activists in the Direct Action Network. This group came together in 1993

as a result of the anger felt by disabled people during the long (and ongoing) struggle for anti-discrimination legislation and full civil rights. At a local level, campaigning for a reasonable standard of core services in areas such as housing and personal support ran alongside more radical efforts to divert funds away from residential care and into the control of disabled people: these efforts were spearheaded by the newly formed Centres for Independent Living (CILs) and Coalitions of Disabled People in Hampshire, Greenwich and Derbyshire.

1.1.1.5 The strands of political action: Radical v Reform

In common with other civil rights movements, the disability movement has developed to encompass diverging strands of opinion on how best to effect political and social change. On the one side there are reformers, who focus on improving current policies through persuasion, lobbying, and research: when new policies are introduced, they base their approach on what is 'realistic' or might be possible to achieve gradually, (Dalley, 1991) without the need for widescale upheaval. Radicals, on the other side, stress the need for fundamental changes to society and are generally impatient with the reformist approach which 'tinkers' with policies they view as piecemeal and not addressing the real issues (Dalley, 1991). The tension between these two sides tends to produce a pragmatic approach to areas of activity like UI: that is, using whatever philosophy or methods best work to achieve the resolution to particular problems or issues (Cherryholmes, 1992; Howe, 1988).

1.1.1.5.1.1.1 The emergence of UI in public policy

In response to disabled people's campaigning for improved representation (and also to the wider development of consumer rights), over the past two decades there have been major changes to the way

health, social services and the benefits system have developed policies which focus on the housing and support needs of disabled people (Means and Smith, 1998; Department of Health, 1989): 'user involvement' and 'participation' have become buzzwords. Legislation and policy statements now stress the importance of enabling those who are in receipt of services to have their say in how those services are run (Barnes, Mercer, Morgan, 2002). Services are expected to be increasingly user or consumer-led, and an emphasis on citizenship highlights people's rights as well as their responsibilities (Beresford & Campbell, 1994).

A fundamental element of being a citizen is the ability "to take part in the decisions that create or recreate the contours of a society" (Drake, 1999, p41) and to participate in the life of one's community on an equal basis with others.

The 1986 Disabled Persons (Services, Consultation and Representation) Act and the NHS and Community Care Act of 1990 specifically highlight the importance of consulting users of services and impose a duty on local authorities to do so. For example, Part III of the NHS and Community Care Act (which covers the provision of community care services) expects local authorities to assess and draw up community care plans in consultation with others, including organisations representing the interests of service users. Furthermore, recent legislation in the form of the Community Care (Direct Payments) Act, 1996, the Care Standards Act 2000 and current Department of Health guidance relating to the 'Valuing People' white paper on learning difficulty services puts the person at the centre of planning and provision with the aim of promoting greater choice and control about the services

they receive and how they are delivered. For example, the "Valuing People" guidance defines Person Centred Planning (PCP) as "a process for continual listening and learning, focused on what is important to someone now and for the future" (DoH, 2001, p1).

Although much of recent legislation incorporates a requirement to listen to disabled people, there appears to be little increase in the numbers of organisations controlled by disabled people that are providing services to users (Barnes, Morgan & Mercer, 2001). An exception to this is in the area of independent living support schemes. These schemes have grown out of the recent Direct Payments (DP) legislation, which itself was a result of the decades of campaigning and lobbying by the disability movement for independent living: it represents a limited but very significant step forward in offering disabled people choice and control over how their personal support needs are met.

1.1.1.5.1.1.2   USER INVOLVEMENT

1.1.1.5.1.1.3

1.1.1.5.1.1.4   What is "user involvement"?

There is a general lack of clarity about what constitutes 'user involvement' and who 'users' are, because everyone uses services of one sort or another throughout his/her life. There is also an increasing trend for public bodies to seek the views of their 'consumers' in the design and delivery of services with the intention of extending the democratic processes of local government and enhancing equality for all citizens (Beresford & Campbell, 1994).

Within the context of this report, the term "service user" will refer to a disabled person who uses a particular 'welfare' service: however, when

discussing UI policy it should be noted that 'informal' unpaid carers are also users in their own right (Twigg, 1994) and there are clear distinctions between the two types of user.

In respect of disabled people as consumers of welfare services, UI exercises can be regarded as attempts to involve them directly in the political, administrative and other processes that affect their lives (Begum & Zarb, 1996). This, in effect, can mean "being involved in many different ways in planning, implementing and evaluating services" (Begum & Fletcher, 1995:20).

Furthermore, for disabled people, it can be argued that having a say in how welfare services are provided and delivered is of fundamental importance: it is not a 'nicety' which they can choose to opt in or out of on a whim as other 'consumers' may do, but rather is a necessity and a right, if they are to receive services which enable them to participate in the life of their communities on equal terms with others.

> "User involvement is a civil rights issue. Community care services determine the quality of people's lives; whether they can live where they choose, participate in personal relationships, engage in activities, which give meaning to life. Often such services are necessary to give people access to very basic human rights." (Morris, cited in d'Aboville, 1995:4).

The shape and level of UI is varied and can be undertaken on a collective or individual basis: whichever form it takes, UI can be viewed as a currency used instead of money to 'purchase' appropriate, efficient services, and to ensure that people get what they need (d'Aboville, 1995:2).

How can the "effectiveness" of UI be measured?

In order to begin to evaluate the effectiveness of UI and the degree of power and control available to disabled people to effect change, Begum & Zarb (Working Paper Five of "Measuring Disablement in Society", 1996) have put forward a 'spectrum of involvement'. This ranges from the provision of information, through to individual or group consultation, the joint working of users and agencies and ultimately to the delegation of control over budgets and services to disabled people. However, to be effective, all of these models require a shift in attitudes and culture, together with the willingness to share or relinquish power. Begum and Zarb (1996) also identify a number of factors that may indicate whether an organisation is serious about consultation with service users and how much value is placed on it: the organisation's approach to tackling such issues as disabling attitudes, access barriers, resourcing UI and its clarity with regards to 'representatives' are seen as key indicators. These indicators will be used as benchmarks in the collection and analysis of data in the following sections.

The funding for UI activities, and thereby organisations of disabled people, is a complex and sensitive issue which is worthy of wider debate and analysis than can be entered into within this thesis. However, before moving on, it should be noted that a number of academics and activists (Barnes, Harrison, Mort, Shardlow, 1999; Barnes, Morgan, Mercer, 2001) have voiced concerns about the dangers inherent in the resourcing of organisations of disabled people, particularly when local authorities (LAs) are the predominant source of income for the voluntary sector. While it is acknowledged that LAs have been very supportive in the development of many user-led groups (Pagel, 1988) there is the real concern that, as a

result, organisations may become assimilated into the existing service system and consequently will be unable effectively or openly to challenge 'the hand that feeds them'. Furthermore, they risk becoming detached from the long-term goals of changing social structures to support disabled people's inclusion as equal citizens (Barnes et al, 1999). This situation should be borne in mind when drawing any conclusions about the effectiveness of disabled people's campaigning.

1.1.1.6

1.1.1.7RESEARCH BACKGROUND

1.1.1.8Previous studies of UI

A limited number of studies have been carried out to evaluate the scope of UI activities: one such is the National User Involvement Project (Lindow, 1999) which took place over a three year period.

The evaluation found that many commissioners were still unaware of the basic aspects of facilitating UI (such as meeting access needs) and as further studies (Vernon, 2002) continue to demonstrate, have little awareness of the cultural and religious needs of minority ethnic service users or how these needs might affect their consultation. The Project also found that when service users were involved, it was more often at a general level than at times of decision-making such as in the commissioning of services, but despite these difficulties the researchers reported that there was a willingness by both service users and commissioners to form partnerships. The Project's report (Lindow, 1999) concluded that there would be major benefits to both parties if resources were made available for outreach work, support and training for users, better to equip them for more meaningful involvement in decision-making processes.

Other studies on related subjects provide a level of insight into the patterns and possible value of UI.

Involving users in their assessment of care

As previously discussed, community care legislation requires disabled people to undergo and be involved in an assessment of need in order to obtain services. However, a study in two LA areas based both on observations of social workers' assessment practice and interviews with disabled people (Davis, Ellis & Rummery, 1998) found that, despite central guidelines, the workers' decisions were often influenced more by conceptions of risk and budgetary considerations than an acknowledgement of legal entitlement or even the preferences expressed by disabled people. The report highlights that, as a consequence, disabled people's experiences of care assessments were confused and fragmented. Often such assessments were felt to be irrelevant to disabled people's own concerns and priorities: more recent studies further confirm these feelings of dissatisfaction (Barnes, Mercer & Morgan, 2001; Vernon, 2002).

Effective user involvement contributes to successful services

The importance of sustaining a meaningful dialogue with service users has been shown to be a complex task that has resource implications (Cole, McIntosh & Whittaker, 2000): however, the cost of funding UI should be viewed as an investment for the future, not least because of the benefits UI brings to both service providers and their client groups, such as developing more appropriate and responsive services.   A number of studies have shown (Lindow & Morris, 1995; Cameron, Harrison, Burton & Marsh, 2001) that where LA and other organisations have a culture of UI and a well-resourced infrastructure of user groups

and consultation forums, departments are better able to sustain user confidence and commitment to change. Furthermore, a review by the University of York (2000) examining the effectiveness of low intensity support services confirmed that when service users are involved in decisions about how a service is organised and delivered, there is an increase in the likelihood that such services would be successful and lead to improvements in the quality of life of its users.

However, although there may be some clear advantages to UI, there may also be some less welcome implications, particularly for those employed in providing a service. A study (Cole, McIntosh & Whittaker 2000) focusing on people with learning difficulties living in four residential homes found that significant amounts of resources could be saved (for example, reductions in costly day centre placements) by responding to people's preferences.   However, the study also found that supporting individuals to develop their leisure and educational interests meant rearranging staffing routines: this required a major shift in attitudes and a willingness to adapt to new ways.

How representative are "representatives"?

The issue of the validity of representation in any consultation or UI activity is a familiar brickbat thrown at disabled people, particularly when they challenge the status quo (Beresford & Campbell, 1994). In reply to such accusations, it could be argued that disabled people's groups are generally more representative than many public sector organisations (Begum & Zarb, 1996): most operate within a democratic process and are accountable to their members. Furthermore, although it is not always possible to represent everyone all of the time, specific attempts have been made within many disabled people's groups to reflect the differing

interests of all people with impairments and to take action to prevent racism, sexism and homophobic attitudes. One recent example of this has been the study carried out by the Warwickshire Council of Disabled People (Evans & Banton, 2001) on developing a strategy for UI among black disabled people. Notwithstanding these good intentions, more effort is needed (by researchers and others) to develop ways to be more inclusive (Barnes, Mercer & Morgan, 2000; Barnes, Morgan & Mercer 2001).

The need for training in involvement

A report carried out by the Social Services Policy Forum (Morris, 1994) found that there were many opportunities within community care policies to promote UI. However, there were also a number of barriers and factors limiting UI at all levels, including complications arising from the range and diversity of need, lack of resources (which can inhibit effective involvement) and the communication barriers which may be present between service users and LA departments. In addition, the need for training and better information was identified for both workers and service users: where training was in place, the researchers reported that experiences and the effectiveness of UI were greatly enhanced: more recent studies continue to highlight this aspect (Lindow, 1999; Baines, Brayshay, Norman et al, 2001).

The factors which tend to inhibit effective UI, as identified by Morris (1994), can be seen as deriving from the imbalance of power experienced by disabled people when dealing with statutory and other bodies. Lack of access to resources, the paternalistic attitudes of professionals and educational disadvantages are some of the elements in the structure of oppression which characterises the situation of

disabled people as citizens within society. In the following section, these issues will be explored in more depth.

1.1.1.9 CITIZENSHIP: POWER AND OPPRESSION

1.1.1.10

1.1.1.11   Citizenship

If disabled people are to be able to take part in shaping and influencing society, then first they must be accepted as citizens with equal rights. Barbalet (1988) argues that within contemporary western democracies, the status of 'citizen' is predicated by the "capacity to participate in the exercise of political power through the electoral process", which involves membership of a community based on "universal suffrage" (Barbalet, 1988). However, if the inequality inherent within a capitalist society hinders the participation of some of its citizens, this will inevitably lead to privileged participation for others: thus some members may be better able to access power and protection, while others such as disabled people, may be socially excluded (Drake, 1999).

1.1.1.12   Power

Power as a concept has been variously defined by sociologists and philosophers as a quantifiable resource and analogous to wealth, as the 'right' or authority to act over others, or as the ability to do or affect something (Parsons, 1969; Weber, 1948; Lukes, 1974). Mann (1986, 1993) sees power as the ability to pursue and attain goals through mastering the environment, either individually or collectively, as exercised by pressure groups. For Foucault (1979, 1982), power is linked with knowledge, which involves the development of discourses: 'power is exercised, rather than possessed'.

Studies in the late 1970s (Grant & Marsh, 1977) have shown that, although prominent lobby groups have access to the highest levels of government (as compared to minority pressure groups), there is little evidence that they are able, in the long term, consistently to influence decisions in their favour, due to factors outside their control. As Drake's (1999) analysis on the formation of social policies shows, the creation and implementation of policy is complex and emerges as a result of multifarious interactions of different interest and pressure groups.

1.1.1.13   Oppression, discrimination and exclusion

Oppression as has been defined by theorists (Barbalet, 1988; Drake, 1999) as the maintenance of power by a dominant group over a subordinate group. The dominant group maintains control of the society's economic, political, and cultural resources, as well as creating a belief system (an ideology that serves to justify and reinforce the status quo) which becomes ingrained as it is passed down to each successive generation in the form of unquestioned "truths" (Giddens, 1977; Young, 1990). The impact on members of the subordinate group, therefore, is that not only do they have limited access to society's resources, but they also experience a definition of reality that serves to maintain their oppression (Andersen, 1988).

A review of the literature produced over recent years by disability theorists (Abberley, 1987; Barnes, 1991; French, 1993; Morris, 1991; Oliver, 1990, 1996; Swain et al, 1993) clearly demonstrates their assessment that people with impairments are confronted by a set of systematic social disadvantages; that they are discriminated against by restrictive structures and practices which have their roots in injustice and subordination, in the same manner experienced by other groups on the

grounds of sex, gender or race. However, for disabled people (unlike other oppressed groups) the biggest obstacles to their inclusion in society are negative public attitudes and material considerations such as the economy and the way it is organised by the mode of production (Oliver, 1996; Barnes, 1997). Furthermore, for disabled people, the dynamics of oppression are deeply rooted in the social and welfare policies of the state: they are evident in the power relationships present in UI, which include issues of control and the roles assigned to users in research formulation (Fisher, 2002).

DISABLED PEOPLE IN RESEARCH

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Objectivity, participation and emancipation

Much has been written about the role of disabled people in research (Oliver, 1992; Barnes, 1996; Stone & Priestley, 1996). Since the 1960s, as the 'business' of disability research has continued to grow, there have been calls by disabled people and disability theorists for the social and material relationships of research production to change (Barton, 1992; Oliver, 1992; Barnes, 1996).

Central to the criticisms of disability research projects is that they have been carried out in a non-partisan and objective manner using empirical methodologies, which is said to have led to

> "the misunderstanding of the nature of disability, the [projects'] distortion of the experience of disability, their failure to involve disabled people and the lack of any real improvements in the lives of disabled people" (Barton, 1992:99).

Even where researchers had made efforts towards power sharing, a number of research activities remained outside the remit of users (Fisher, 2002). Fisher cites studies by Rapp et al (1993) and Whitmore (1994) as examples of research that involved service users in much of the process, but not in the final analysis or writing of reports, and thus the outcomes remained under the control of 'professional' researchers.]

To counter these criticisms, the emancipatory research paradigm has been put forward by Oliver (1992) and others. Its key feature is the "rebuttal of positivist and interpretative claims to objectivity and assertions about the political positions of the researcher" (Stone & Priestley, 1996). Furthermore, it is claimed that emancipatory research should be transformative: that is, the research process and its outcomes should be of benefit to those being researched, if it is to provide a radical alternative to mainstream theory and methods (Oliver, 1992). Unless disabled people are involved in determining the aims, methods and use of research, then clearly it does not empower the researched group or have transformative potential (Zarb, 1992).

Against this background there has been a gradual move towards enabling some disabled people to be more actively involved in research and to begin to have control over some of the process. However, the question of involving people with learning difficulties in research has invariably been viewed as too complex to resolve, and until recently they have tended to remain on the periphery (Richards, 1984; Aspis, 1997). Over the past two years a small number of projects have aimed to address these issues. One of these, which took place in 2001, involved a team of people with learning difficulties who visited five projects in England and Wales to identify what services were available and how

people with learning difficulties were involved in their operation (Baines, Brayshay, Norman, Roy, Wallis, Walsh, 2001). The team were not surprised to find that people with learning difficulties were rarely involved in getting new ideas started, in managing the service or in making decisions.

1.1.1.13.1.1.1   Using research paradigms to evaluate UI

For Oliver (1992, 1996), the value of research can be gauged by asking whether the process of participation for the disabled person was an empowering one, how the work has made a contribution to individual or collective empowerment and whether improvements in the lives of disabled people have been achieved in any measure as a result of this participation. This study will attempt to apply this paradigm to wider UI activities in order to assess their value to disabled people, bearing in mind that even when service user involvement and participation in social care research are central, the process is still "capable of leaving the service user a long way short of being empowered by research participation" (Fisher, 2002).

CONCLUSION

The above review of literature and policy change describes gradual but limited progress in the empowerment of disabled people. In the 1970s, disabled people were perceived to be passive recipients of (largely medical) services. Over the past two decades, the campaign for civil rights has had some success, for example in redefining disability in terms of discrimination, in dismantling structures which led to residential 'care' and in pushing for the funding of personal assistance to be paid directly to the disabled person. In parallel, moves to transform public services

into consumer-led agencies have created opportunities for disabled people to contribute to policy formulation and so, in theory, shape the services they use. Indeed, legislation requires users of services to be consulted. But does the current climate of "listening and involving" actually contribute to the empowerment of disabled people?

The following chapters describe the design, execution and results of a small-scale study examining disabled people's experience of UI. This study will then provide the basis for an analysis which aims to go some way towards assessing the impact this increased involvement is having, not just upon the services that are provided, but in promoting the wider civil and human rights agenda.

1.1.1.13.2 Chapter three: Study design

1.1.1.13.2.1.1

1.1.1.13.2.1.2   This chapter contains an account of the research

strategy and the theory which underpins it, the methodologies

used to collect the data and the means by which participants

were selected.

1.1.1.14   AIMS

The aims of this research project are

- to evaluate disabled people's experiences of being involved in

research and consultation projects and

- to assess (from disabled people's perspective) the impact of UI

practices over the past two decades, by identifying tangible signs of

change.

1.1.1.15   THE APPROACH

Historically, people with impairments have been (and continue to be)

discriminated against in all areas of their lives (Barnes, 1991) and, as

with other 'subordinate' members of society - women, people from

minority ethnic communities, gay and lesbians - disabled people belong

to an oppressed group. Accepting this as the ontological perspective,

the social model of disability (see chapter one) will be the underpinning

epistemology for this research, using methodologies appropriate to both

participatory and emancipatory practices that value "people's first-hand

direct experiences as a basis for knowledge" (Beresford & Evans, 1999).

Central to this philosophy is the empowerment of the research 'subjects' and reciprocity between the researcher and those being researched: this has been the approach employed, wherever possible, within this project. Furthermore, in order to avoid the research being viewed as intrusive or oppressive, every effort has been made to ensure participants were comfortable with, and able to express their preferences about, the methods of data collection and analysis. However, other factors including resource limitations and time will influence how far this intention has been fulfilled.

1.1.1.16   LITERATURE REVIEW

Information from a variety of sources was collected and analysed (see chapter two above), to examine the history of disabled people's involvement in both service provision and disability research and place it in context. Relevant terms were defined and some examples of the different types of UI currently or recently in use were set out. Information was collected from:

- published material, books and journals;
- internet and library resources;
- unpublished regional papers and reports.

1.1.1.16.1.1.1   RESEARCH STRATEGY AND DESIGN

1.1.1.16.1.1.1.1.1

Triangulation

Denzin (1988) describes triangulation as the use of three or more theoretical perspectives, investigators or data sets for research on one theme or issue. This study utilised both micro (interviews, focus group) and macro (surveys, literature review) level approaches, enabling

comparisons to be made between data on the same topic derived as a result of different methods. Such comparisons alone cannot be relied upon to validate findings (Bryman, 1992; Bloor et al, 2001) but triangulation can reveal common themes or emerging issues. Robson (2002) acknowledges that the use of multiple research methods may add to confusion but despite this, it reduces the 'inappropriate certainty' that may occur when using single methods. Triangulation is particularly useful in exploratory studies such as this, which does not set out to provide the 'truth' or a single answer to complex and subjective issues, but provide a range of views and a 'snapshot' for further development.

Qualitative methods

The study's aim was to gather data on service users' perceptions of consultation, UI practices, their ability to influence change and satisfaction with the processes involved.

In order to provide an in-depth analysis of the views of disabled people as consumers of services in an exploratory study such as this, a number of qualitative methods were considered, including interviews in various formats and small "focus group" discussions. While qualitative studies are less useful for discovering overall patterns and structures, the flexibility in their design allows the discovery of a richer and deeper understanding of the process of change in society (Bryman, 1988) They also provide an opportunity to undertake descriptive explorations of both methodology and the subjective meanings given by participants.

In this type of qualitative research, it is not intended that all interviewees should be asked questions on all of the areas, rather that

"the researcher explores a few general topics to help uncover the participants' views but otherwise respects how the participant frames and structures the responses" (Marshall & Rossman, 1999).

There are a number of advantages to the use of focus groups; they allow for the efficient collection of qualitative data from several people at the same time, provide natural quality controls and permit the fairly simple assessment of consistent or shared views (Robinson, 1999). Possible negative effects of the use of focus groups include the obvious limitations to the number of questions that can be asked. In addition, group dynamics and power hierarchies may affect who speaks and what they say and, unless skilfully managed, there is the danger that the group/discussion will be dominated by one or two people (Robinson, 1999).

Despite these weaknesses, when properly facilitated, focus groups can be an enjoyable and empowering experience; enabling people who may be reluctant to participate as individuals to come together, be listened to, exchange views and be stimulated by others ideas (Robinson, 1999). This has proved to be an effective method for including people with the label of learning difficulty (Baldwin, 1997).

Quantitative method

In order to obtain information about a wider range of UI activities in which organisations of disabled people had participated over the last five years, a quantitative fixed design approach, in the shape of a survey, was deemed the most appropriate method. Fixed designs are more effective in examining the structural aspects of society and best suited to establishing relationships between variables, but are weak in determining

the reasons for them (Bryman, 1992). Flexible research is more effective in dealing with processes and developing explanations. Therefore, combining qualitative and qualitative methods leads to a more complete picture (Bryman, 1988, 1992).

Surveys can produce large amounts of easily managed data, at low costs and in relatively short time scales: they also have the advantage of offering respondents anonymity, which encourages frankness, particularly when commenting on sensitive issues. However, the response rates to surveys are typically low, misunderstandings due to poor survey design and wording may lead to ambiguities, and the answers given may not reveal the true attitudes or beliefs of those being surveyed. Despite these disadvantages, Hakim (1987) advocates the use of surveys because

> "they are accountable and provide a transparent record of the methods and procedures used … so that the implementation as well as the overall research design can be assessed". (Hakim,1987:48)

1.1.1.16.1.1.2   SAMPLING

Qualitative methods

Two recent projects which were viewed as being 'user led', were identified as sample sites for this study. Both projects had involved disabled people in a variety of ways (principally as researchers and contributors) and had attracted attention from academics and practitioners based outside the locality in which they were carried out. Both projects had disseminated their findings through public launches to their constituents and interested agencies, and also through the circulation of summary reports. There were also more practical reasons

for choosing these two projects: they were both within reasonable travelling distance and contact had already been established through previous work with the organisations' members. As a consequence of this relationship, levels of trust had been developed, that is to say, 'confidence in the reliability of a person or system' (Giddens, 1990) and contributors thus felt at ease to talk freely with the researcher: in addition, savings were made on time, energy and limited resources. It should be noted that the researcher does not make any claim that this study and the project sites sampled are representative or that the subsequent findings provide substantive evidence in their own right, but rather that this study seeks to offer some insights into current UI activities which could be further explored in more detail in future studies.

All of the participants in the qualitative part of the study were self selected from among contributors to the two projects under review. However, a preference was expressed by the researcher that there should be a balance of men and women, which would reflect the composition of the original research/review project teams.

1.1.1.17

1.1.1.18   Quantitative method

For the purposes of this small scale study, it was felt to be important to include established organisations in the survey group, as well as those that have emerged over the last ten years. The intention was also to include a mix of larger agencies with several staff and smaller (grass roots) groups which might only employ one or two paid workers.

As a starting point, nine organisations were selected for inclusion in this survey. These groups had participated in the third stage of the "Creating Independent Futures: An Evaluation of the Services led by Disabled

People" (Barnes, Morgan, Mercer, 2001), a two year research project carried out by the Centre for Disability Studies, Leeds (CDS) and the British Council of Organisations of Disabled People (BCODP). The project's report (Barnes et al, 2001) states that the sampling criteria used for focusing on these nine organisations were the year of establishment, size of membership, user numbers, geographic location, and range of services offered *(Appendix2).*

However, as the response to this first survey attempt was low, further organisations were included, in order to provide a wider collection of data to be analysed. The second tranche were all members of BCODP and, as far as possible, fulfilled the same sampling criteria as the first group surveyed: however, it should be noted that the second list included a higher proportion of relatively newer groups and these may not have had as much experience in consultation or research.

1.1.1.18.1.1.1   DATA COLLECTION

Qualitative methods

To avoid the research being viewed as oppressive and to put individuals at ease, participants were asked how they preferred to be interviewed: individually, in pairs or as a focus group. Those who opted for individual interviews were then offered a choice of face to face, telephone or email interviews. As a result, data was collected by means of three semi-structured telephone interviews and a small focus group discussion.

In order to facilitate the meaningful participation of people with learning difficulties (who were involved in the second sample project under review) participants were asked how they would like to be involved and

by whom (if anyone) they would like to be supported. Following a brief discussion among the potential group, it was agreed that participants would be most at their ease if the meeting was held in their organisation offices over lunch. Supporters were chosen by the participants and were people with whom they were familiar (a paid worker and an advisor to their organisation).

The researcher recognises that it is accepted practice to acknowledge the value of disabled people's participation in research by offering a nominal fee. However, all of those involved in the focus group and individual interviews stated they were happy to assist without payment as the study was funded by the researcher and was for academic rather than commercial purposes. The members of the focus group agreed to accept payment for a sandwich lunch, as this enabled people to attend who would usually have been elsewhere at this time.

After an initial informal discussion with the researcher, during which the aims and objectives of the study were outlined, participants were given the opportunity to ask questions and clarify their roles within this exercise. The researcher gave assurances that all information received would be treated with confidence and sensitivity and would not be attributable to any individuals or organisations. An information sheet was also provided for those who wanted a written copy of the objectives. A time convenient to the interviewees was arranged and consent was given either verbally or in writing before the interviews/group discussion took place, and again at the start of interview, with an opportunity to withdraw at any time.

The interviews were structured around the key themes identified in chapter two: previous experiences of UI, current experiences of a specific project including access issues, training, ownership, influence and expectations. (Appendix 1)

The focus group discussion followed a similar pattern to the individual interviews as well as providing an opportunity to talk about emerging issues and concerns (Appendix 1)

A copy of the proposed interview questions (in plain text and pictures) was circulated in advance to the focus group and their supporters, to enable participants to be prepared for the meeting.

The three individual interviews lasted about 45 minutes each and the group interview was of 150 minutes duration. All of the interviews were recorded and notes made. The key points from the notes were read back to the interviewees for verification and to provide the opportunity to add anything further to their original responses, which resulted in a small number of amendments and additions being made. A similar process was used to verify statements with the focus group.

1.1.1.18.1.1.2

Quantitative method

Positive changes as a result of UI may quite often only be visible after a number of years, particularly if they involve restructuring services or making major policy changes. Questions designed to produce this information were incorporated into the design of the surveys sent to organisations of disabled people: they covered type of involvement and the nature of the projects included, who initiated it, whether individuals gained or felt empowered by the process, whether they had been

listened to, what outcomes they expected and their overall satisfaction with the process.

All of the organisations that were sent surveys by email or post received a covering letter explaining the purpose of the survey, how it would be used and assuring respondents of anonymity and sensitivity when collating and analysing the data. The return of surveys was deemed to be consenting to participate in the study as described in the cover letter. No payment or other inducement was offered to respondents as there were no resources to cover this. However, all of those who returned surveys were offered a copy of the summary findings at the end of the project and were thanked for their time.

1.1.1.18.1.1.3   CONCLUSIONS

The methodology for the interviews, focus group and surveys evolved as the research process unfolded, and this flexibility was essential in order to overcome setbacks and change, and explore how best to enable all participants to participate in a meaningful way. The data derived from the interviews and surveys are summarised in the following chapters (four and five).

1.1.1.18.2 Chapter four: Qualitative research findings

This chapter provides an outline of the two projects examined, commentary on the limitations of the study and a summary of findings.

THE SAMPLE PROJECTS

Both the user-led Best Value Review of Direct Payments (BV Review) and the research project involving people with learning difficulties (SA Research) had involved disabled people in a variety of ways, principally as researchers, interviewers and contributors. The projects had also either been initiated by disabled people or were viewed as user-led.

1.1.1.18.2.1.1   The BV Review

This project was part of an local authority (LA) "Best Value Review" of the Direct Payments process, which also included the user-led Support Service for Independent Living: it was undertaken between June 2000 and June 2001. The Review was funded by the Joseph Rowntree Foundation: it was jointly managed by a disabled person from the local service user organisation and the research partnership manager from a nearby university. It is worth noting that an earlier funding bid by the local service user organisation alone was not accepted. However, it was suggested that if a second proposal were submitted it would be received positively, providing it had the support of, and was co-managed under the auspices of, an academic body.

A disabled person with a research background was employed as project researcher, to co-ordinate and facilitate the participation of a group of

disabled people, thus enabling service users to undertake many of the tasks required within the national BV framework. Training and support was provided and user costs met in full. The findings of the project were disseminated via a published guide to service user led reviews and a summary of the Review was posted on the LA's website, following formal acceptance by the Social Services Committee.

1.1.1.18.2.1.2   SA Research

The SA Research project was the result of an invitation to tender from the same LA to a self-advocacy organisation in a neighbouring authority area. In preparing their tender for the County Council, members of the SA organisation were keen to be actively involved in undertaking the research. However, they recognised that a considerable amount of data collection was called for, a task that they did not feel confident they could carry out alone. To resolve this, the group approached two researchers with whom they had worked on a previous occasion and who had connections with a unit specialising in learning difficulty studies: a working partnership was formed.

The organisation was then granted the contract to undertake a major consultation exercise in 2001-2002 with people with learning difficulties within the LA's area, in order to map services currently used and to provide a tool for future planning. Training and support was provided and a small 'research' team of people with learning difficulties carried out interviews and group sessions with service users. A report was subsequently produced and members of the research team from the self advocacy group took part in the dissemination of the findings.

1.1.1.18.2.1.3   Impact of these two examples of UI

The BV Review has already had a measure of impact. For example, additional training sessions have been run to increase the knowledge and awareness of the DP scheme among care managers, and also a commitment has been made by the local social services department (SSD) to fund the establishment of a Monitoring Group (within which service users will play a significant role) to oversee the implementation of the recommendations made by the review group. However, the group were unhappy with the way a number of their recommendations were quickly 'seized upon' and used to make changes that went against the spirit, if not the purpose, of the review.

The focus group (drawn from the SA Research team) have expressed disappointment that the findings of their report do not appear to have been used to inform policy or influence changes to services. Furthermore, the LA has recently commissioned more research, covering similar ground, from a professional consultancy company that does not appear to have any direct connections with disabled people.

1.1.1.18.2.1.4   Tensions

Both of these sample projects have required disabled people as service users to form partnerships with non disabled researchers and this relationship was the cause of varying degrees of tension in each. For example, the roles of the two people acting as joint managers of the BV Review were the subject of some confusion among the user project group and within the LA itself. During the SA Research project there were also tensions between the professional researchers and the user team, due mainly to poor communication between the two groups and also the feeling that the non-disabled partners were taking a more

prominent role than that which was originally agreed. In fairness to the 'professional' researchers, it should be noted that only the views of users have been included here as the purpose of this study was to evaluate disabled people's perceptions of being involved in research. However, in future studies it would be interesting to explore how they viewed their roles, their motives and the power relationships within such partnership arrangements.

1.1.1.18.2.1.4.1.1   PROFILE OF PARTICIPANTS

Four males and two females took part in the interviews or focus group: the focus group was made up solely of men. Their average age was within the 35 to 45 year age group. The individual interviewees all self-defined as having a physical impairment and the focus group defined themselves as having a learning difficulty. All participants had taken part in one of the two sample projects during the past 18 months.

1.1.1.18.2.1.5   LIMITATIONS OF THIS STUDY

This research was undertaken as part of an academic project, and as such, it was subject to limitations in terms of time and resources. These limitations have affected the extent to which the researcher was able to fulfil her intention to work within the emancipatory research paradigm (see chapter two). Although the researcher was a disabled person, and was committed to the social theory of disability, it would be inappropriate to claim that the fieldwork undertaken for this study was user led. However, every effort was made to ensure that participants did not find the research process oppressive and, wherever possible, the methods employed respected individual preferences and opinions.

The projects and groups under study were, of necessity, selected by the researcher and the participants (both in the focus group and individual interviewees) were self-selected, introducing the possibility of sample bias and lack of objectivity. Nevertheless, this was principally an explorative study, and as such has highlighted emerging issues and themes as well as providing some pointers towards possible further research in this area.

SUMMARY OF FINDINGS

This section is a report of the combined individual (BV Review) and focus group (SA Research) interviews. To protect identities, pseudonyms have been used when attributing direct quotations.

1.1.1.18.2.1.6   Previous experience of UI activities

All interviewees (both individual and focus group) stated that they were members of service user led organisations and had participated in a number of UI exercises over the past few years. However, they all commented that due to the high demands for UI by statutory agencies, they have become more selective about their involvement. Limited energy levels and low levels of interest in the topics under discussion were key considerations for two interviewees.

> *"It has to be within my own interests and where it is possible to make a difference." (Sian, BV interviewee)*

When interviewees were asked whether they felt they had made a difference, there appeared to be a consensus that in the past little seemed to have changed as a result of their involvement.

"On the few occasions I had been to meetings, I did not feel it made much difference - just filling a space." (Mary, BV interviewee)

The SA focus group said that they felt it might be useful to be involved in some meetings, but even in these cases they expressed reservations, as meetings tended to be too long, access needs were not always met, people did not listen to them and jargon was often used.

While there were clear doubts expressed about the benefits to service users of attending every meeting, there was also an acknowledgement that UI was a 'necessary evil'. Three of the BV interviewees said they felt it was important to go to certain meetings on behalf of their organisation because future funding could depend on their participation. Equally, the SA focus group said that they recognised that Partnership Boards (for example) had both the power and access to resources directly to influence services, and therefore it was in disabled people's interests to make sure they were part of that process.

1.1.1.18.2.1.7   Roles within the projects under study

All three BV Review interviewees described their role as project group members: they had designed surveys, assisted with collecting information (including interviewing staff from the SSD), helped to interpret the surveys and presented the findings to the LA. Two people said that they had also given a presentation at the national launch of the project's report. Asked why they had become involved in this specific project, the interviewees stated that this was primarily because of a personal interest in the subject, but also because they had confidence in the user-led nature of the project.

The SA focus group said that they had formed a research team and had been involved in speaking to service users, working on interview questions and surveys and in disseminating the findings through a launch of the report. Key motives for undertaking the work identified by the focus group were:

- to ensure people with learning difficulties were centrally involved and their views were 'listened' to,
- to provide a source of income to their organisation and
- to demonstrate to future funders the potential and skills within it.

1.1.1.18.3 Information

Interviewees were asked if they had received enough information about the projects and whether they felt they could make any changes to the design if they wished. They commented that there was more paperwork than expected, but users did control the project as far as possible, within the BV framework and with the benefit of hindsight, more information on the commitment involved would have been useful.

1.1.1.18.3.1.1   Access, payment and training

Respondents said that all access needs were met and service users were able to take part in a meaningful manner. For example, support was provided to enable people with learning difficulties to be actively involved and interpreters were provided for two deaf/blind users. However, there was some regret that the project group did not have any members from a minority ethnic background.

"It was a learning experience for us as we had to think about how we did things and include everyone's views – it wasn't always easy . . . but it was important for us to be aware of other disabled people's

access needs as well as our own as not all of us had thought much

about it before." (Mary, BV interviewee)

All interviewees said that they were offered and accepted training and advice to help them to be able to undertake a number of the research activities and that they received payment for their time and travel costs.

"Training was very good, but would have liked to have had a bit more

to see what other local authorities do in their reviews." (Tim, BV

interview)

1.1.1.18.3.1.2   Barriers to research – attitudes and respect

Everyone said that there were times when they were not listened to, or their roles as user interviewers/researchers were not respected by care managers and other professionals. Significantly, all of the respondents highlighted the obstructive nature of managers, which caused unnecessary delays and made users feel undervalued. In one instance the mainly attitudinal barriers which prevented research taking place were only overcome when the Director of Social Services intervened.

"There were difficulties . . . it was a real shock to them and there was

definitely resistance from certain managers." (Tim, BV interview)

"Our research team felt that . . . in some cases they felt they were

stopped from getting access to service users, despite the study being

commissioned by the [LA] . . . time was lost due to resistance."

(SA focus group)

1.1.1.18.3.1.3   Empowering experience, benefits to individuals

Despite the setbacks and negative attitudes of the 'care professionals', all those who took part in the BV Review said that they felt it had been a positive and empowering experience, because they had gained a

number of insights into internal processes to which they would not normally have had access.

"I liked doing the interview with the social worker – it was strange to be asking them the questions."

(Sian, BV interviewee)

However, those people who had been part of the SA Research team were less positive in their feedback.

"We know for next time that we have to be very clear about what they expect us to do and we tell them how we are going to do it . . . we were not the enemy!" (SA focus group)

When asked to explore further whether they felt the experiences had made them more confident or if they had gained new skills which they could use in other areas of their lives, all interviewees responded positively.

"I personally got a lot from it. I felt much more confident both in myself and what I could do. It made me realise that I had skills I didn't know I had and helped me to mix with people much better as I usually tend to keep to myself." (Sian, BV interviewee)

"I felt it was quite liberating to be able to be critical of services and know that these views were being taken to highest levels." (Mary, BV interviewee)

Members of the SA Research focus group mentioned the following personal and organisational gains:

- *new skills and confidence*

- *met people wouldn't normally get chance to see*

- *visited new places*

- *more people know about self advocacy*

- *good to be able to influence things from the outside even if it did not feel like that at the time!*

- *power of working as a group*

  "We have learnt a lot about how social services contract systems work – we will be better prepared and know what questions to ask before we do anything like this again!"   (SA focus group)

Significantly, one participant from the BV Review said that he had not thought of himself as being a 'political person', but as a consequence of his participation in the project, he had began to recognise the discriminatory way in which disabled people are treated.

  "I have become more aware that DP users and disabled people generally are expected to be accountable all of the time, for every aspect of their lives, which wouldn't be accepted by non disabled people, just because we need to use services in order to have a reasonable quality of life . . . if only SSD and others understood how frustrated, dependent and sometimes angry this makes us feel."
  (Tim, BV interviewee)

1.1.1.18.3.1.4   Any improvements?

When asked if they felt the conduct of the projects could be improved upon, the interviewees mentioned feeling 'rushed' and 'under pressure at times', and suggested that more time should be allowed in the design and planning of future research.

  "The only thing was running out of time at the end – that was as much to do with their timetable as our communication issues." (Sian, BV interview)

Members of the focus group identified the following difficulties:

- *attitudes of staff - their resistance*

- *lack of LA information gathering systems and the need to start from scratch*

- *time constraints – having to work to someone else's timetable is unrealistic if users are doing the work and being effectively involved*

- *funding for this work did not reflect the amount of work or the real costs*

1.1.1.18.3.1.5   Would you do it again?

All participants felt the projects had been worthwhile and a good use of time. They also said they would 'do it again', but several people mentioned a number of conditions which would have to be met before they committed themselves to new projects in the future.   These were:

- must be good support and facilitation

- only if interested in the subject

- must be more than a token exercise

- must be a clear timetable

- must be clear what the commissioner wants

- must be a commitment to use findings or act upon recommendations in a way that respects and values the principles behind them

1.1.1.18.3.1.6   Expectations

BV Review interviewees felt positive about the impact of their report, as money had been allocated for a Monitoring Group to oversee implementation. They were looking forward to an increased take-up of

Direct Payments and pleased with the nation-wide response to their report, but aware that pressure would have to be kept up.

> *"We need to keep pressing the LA – I fear that if we let up for a minute, things will slip back, would say there was 50% chance of things improving in the long term." (Sian, BV interview)*

The SA Research team members were more pessimistic.

> *"It's been some months since the report was handed over, but we have not had any feedback or further contact about it, which is a shame."*

It was felt that staff at all levels must be involved in such exercises, not just top management, and that the LA lacked the money to implement the report, which was probably the reason it had 'gone quiet' about it.

1.1.1.18.3.1.7   Anything to add?

Asked if they had anything to add, all BV Review interviewees said they felt betrayed by the use of one aspect of their work. They had recommended improvements to the Direct Payments support service, and instead the contract had been put out to tender, resulting in cost savings to the LA but delivering a service remote from service users and staffed by non-disabled people.

> *"It's disappointing as we were very strong on that, saying not just run by an organisation controlled by disabled people but to have staff who were either DP users or disabled people, this hasn't happened. Seems like they have cherry picked and have taken up some of the recommendations which they could do without too much hassle or cost." (Tim, BV interview)*

1.1.1.18.3.1.7.1.1   KEY POINTS

Regarding UI generally, participants expressed:

- increasing selectivity regarding participation in UI projects

- sometimes a feeling of being used

- projects need to make a difference and be relevant

- some meetings are a necessary evil to get funding for group or wider disability community

Regarding the specific projects under study:

- users were meaningfully involved and had some measure of control

- training useful, access needs met

- a good deal of resistance was encountered from SSD managers

- empowering experience, felt able to criticise

- the exercise had raised personal political awareness

Lessons for the future included:

- meaningful involvement takes time

- would do it again if well supported, defined, not a token exercise

- need to keep up pressure

- findings can be misused

1.1.1.18.4 Chapter five: Quantitative research findings

This chapter presents a summary of survey responses.

METHODOLOGY AND RESPONSE

Using quantitative methods in order to collect a wider range of data for analysis, a small-scale postal and email survey of 22 organisations of disabled people was undertaken, to ascertain the types of UI activities they had been involved in and to evaluate the range of involvement, satisfaction and overall outcomes. The questions were based on those used in the interview schedule but with a focus on projects completed within the past five years. See chapter three for details of sampling criteria.

Of the 22 surveys despatched, 11 were returned. Each organisation had the opportunity to comment on up to six projects and from these 11 returns, 44 projects were identified as suitable for statistical analysis.

SUMMARY OF FINDINGS

### 1.1.1.18.4.1.1   Project details

Of the 44 projects in the survey, 33 had been completed in the past two years or were ongoing. The high number of ongoing projects resulted in some respondents being unable to assess outcomes.

Table 1: Year of project completion
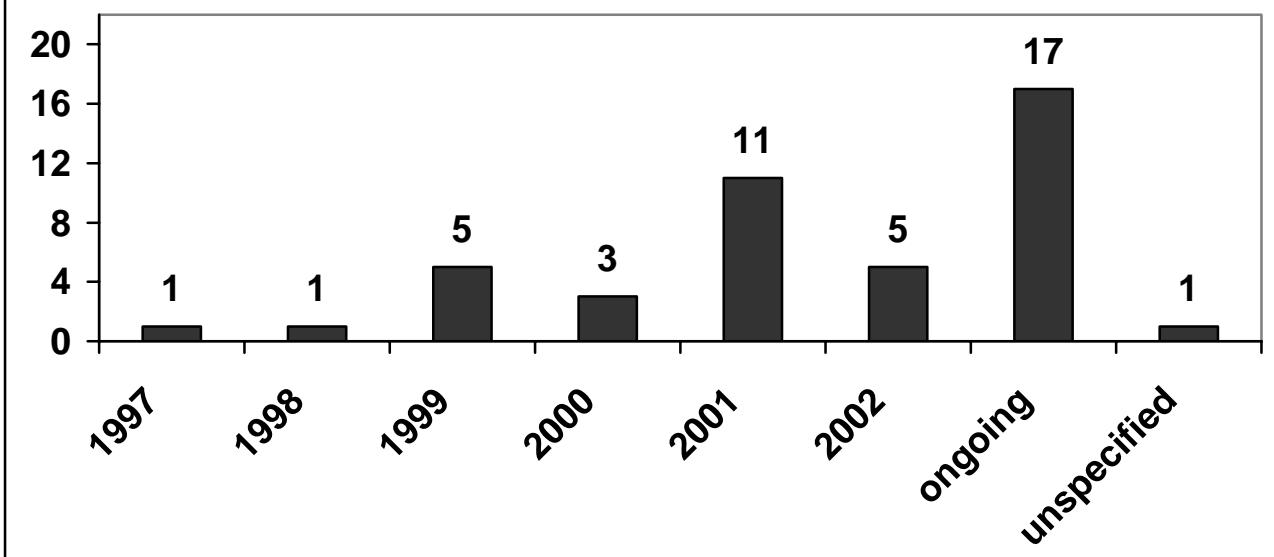
1.1.1.18.4.1.2   Range of UI activities

Collated responses revealed that organisations had participated in a wide variety of UI activities, with a number of different agencies and at varying levels of participation. This UI ranges from 'supplying' one participant to attend a local health authority meeting, to working jointly on steering committees overseeing projects such as developing a trading exchange scheme, computer access, setting up a call centre, through to playing a significant role on the national care standards task force or in major pieces of research.

Independent living is a major focus of UI activity, probably as a result of recent legislation. Education, employment and transport account for only 9% of projects, although these issues are very significant for disabled people.

Table 2: Type of project

- ■ DP/Ind living (14)
- ▦ Health (4)
- ▨ Education/employment (3)
- ☐ Transport (1)
- ▨ Day services (3)
- ▨ Community initiatives (5)
- ▨ Staff training (2)
- ▨ Women's projects (2)
- ▨ Unspecified (10)
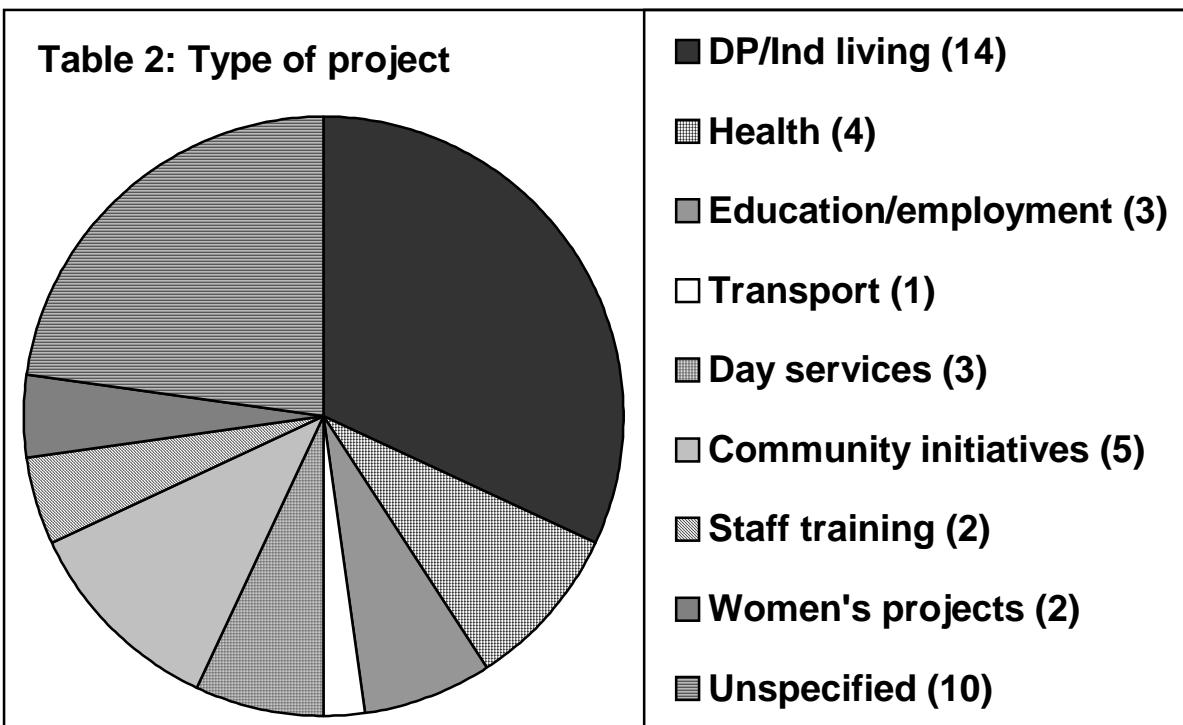
Only six projects did not involve an LA. Most of the remaining 38 were carried out (in some way) in conjunction with the local SSD: these covered Direct Payments and support services, care reviews, day care services and staff training. Involvement in wider community initiatives (5) indicates that disabled people are raising their profile as a group within the local community.

Only two health projects involved consultation with local NHS authorities, which seems a very low number when compared with SSD activity. At a national level, two organisations had been consulted by the Department of Health.   However, these opportunities tend to be limited to larger organisations and some respondents identified that there was work to be done at a local level.

Nearly half the projects had been carried out within a partnership structure, usually with the local SSD or other LA departments.

Table 3: Nature of participation
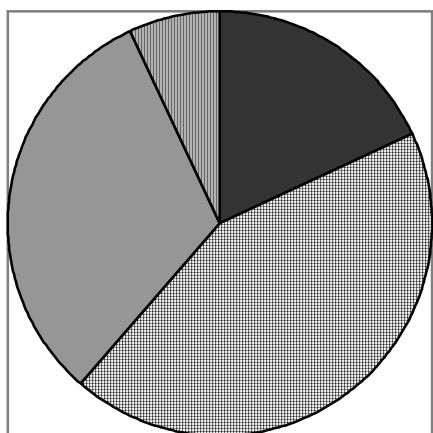
- ■ **Lead organisation (8)**
- ▦ **Partner organisation (19)**
- ☐ **Supplied participants (14)**
- ▥ **Other (3)**

1.1.1.18.4.1.3   Satisfaction with the conduct of the project

Respondents were asked to rate their satisfaction with the way the specific projects were carried out, in terms of feeling whether participants were listened to, had their access needs met and if they were able to influence the projects' design. For the great majority (34 projects) satisfaction was rated as average or above.

Table 4: Satisfaction with conduct of project

	1 (low)	2	3	4	5 (high)
	6	4	13	8	13
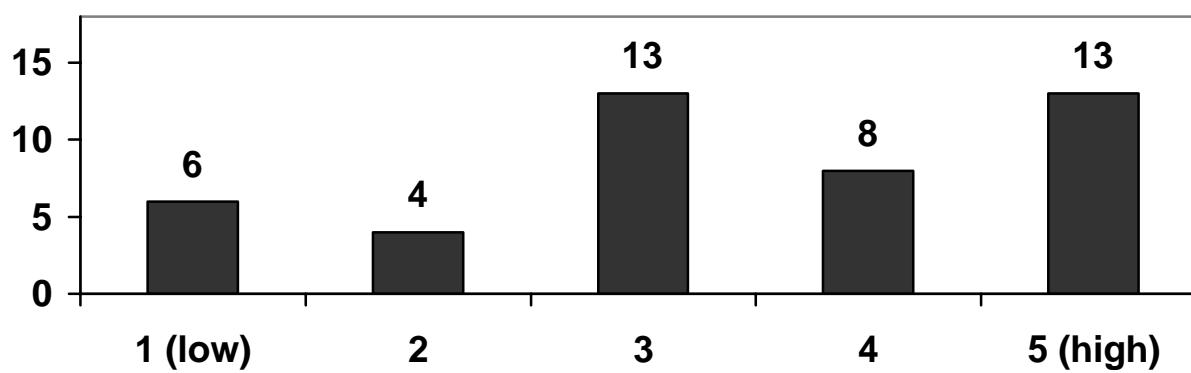
When satisfaction is analysed by the nature of organisations' project involvement, it can be seen that higher satisfaction levels were achieved when the organisation had a more active role.

Table 5: Satisfaction/nature of involvement

Legend:
- Other
- Supplied participants
- Partner organisation
- Lead organisation
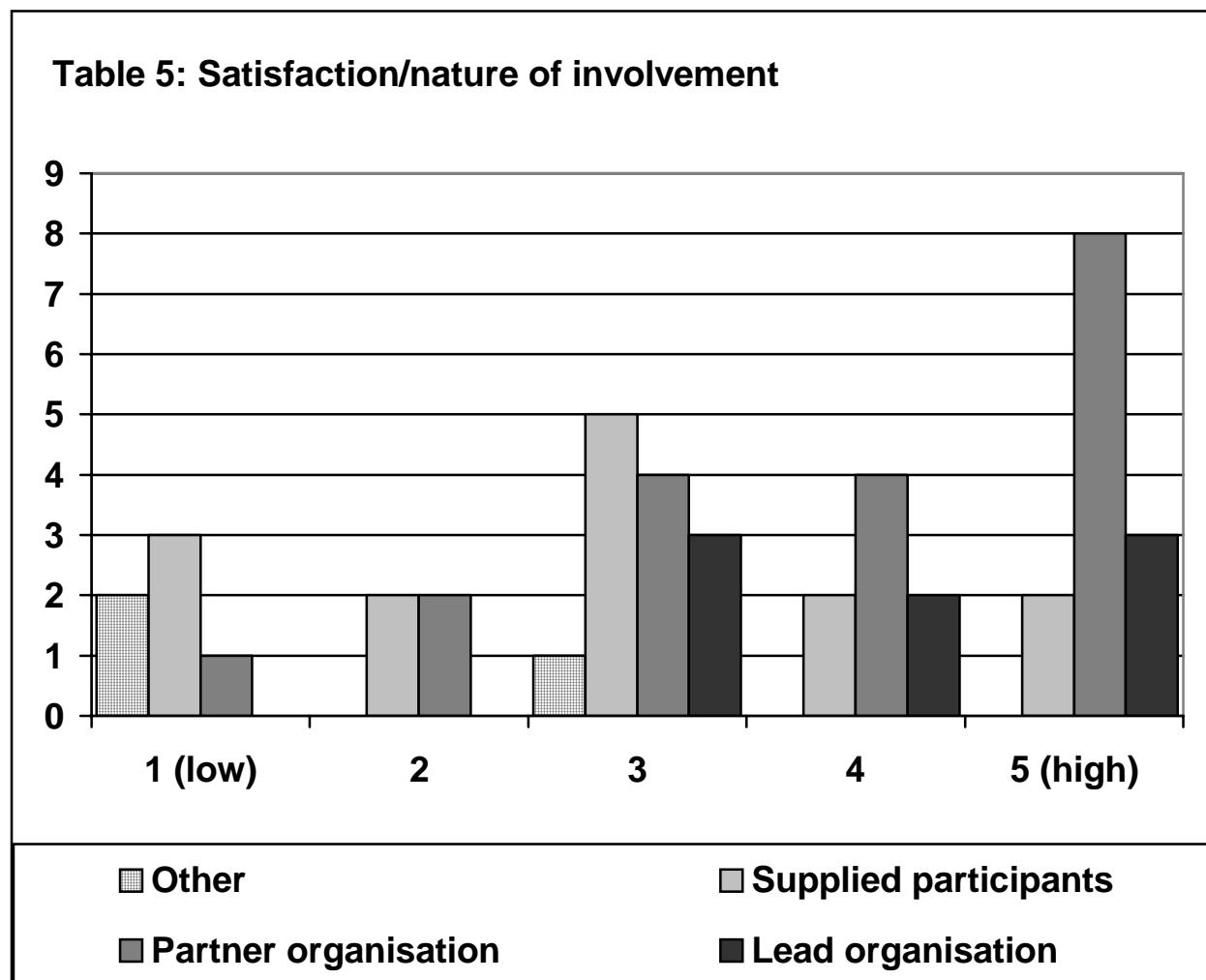
Respondents' comments on their experiences in this section revealed some ambiguities behind the average satisfaction rating:

"SSD didn't service meetings well. Financial limitations led to compromises. Sometimes the agreed outcomes of meetings were effectively ignored and changes made to the project regardless.. Despite this, we were on the whole able to influence the shape of the project in a positive way."

Respondents who gave a low rating were usually very unhappy:

"We were not listened to, no follow up, no UI in action plan, very
unhappy - they had to redo the plan as it contained inaccurate
information."

"Tokenistic in the extreme."

However, some partnership arrangements were very highly rated, and a
number of respondents seemed pleasantly surprised by the performance
of those with whom they were working:

"The purpose was made clear, the organisation's costs were fully
met, the meeting was receptive, well focused and accurately
recorded."

"Pleased with outcomes, worked as a partnership."

1.1.1.18.4.1.4   Perceptions of the experience of UI

Respondents were then asked four questions which explored their
perception of the value of the projects surveyed. These were:

- Has the project had a positive effect on people in your area?

- Have there been any concrete outcomes from the projects surveyed?
  (These might include changes in policy or practice by service
  providers, more resources or more opportunities for disabled people's
  involvement.)

- Overall, was this project a positive or negative experience for your
  organisation?

- Do you believe that this involvement promoted disabled people's
  rights or contributed to the wider agenda?

As the chart below illustrates, respondents largely saw their experience as either positive or negative, there was very little differentiation in the scores given to concrete outcomes and more intangible benefits.

Table 6: Perceptions of the experience of UI
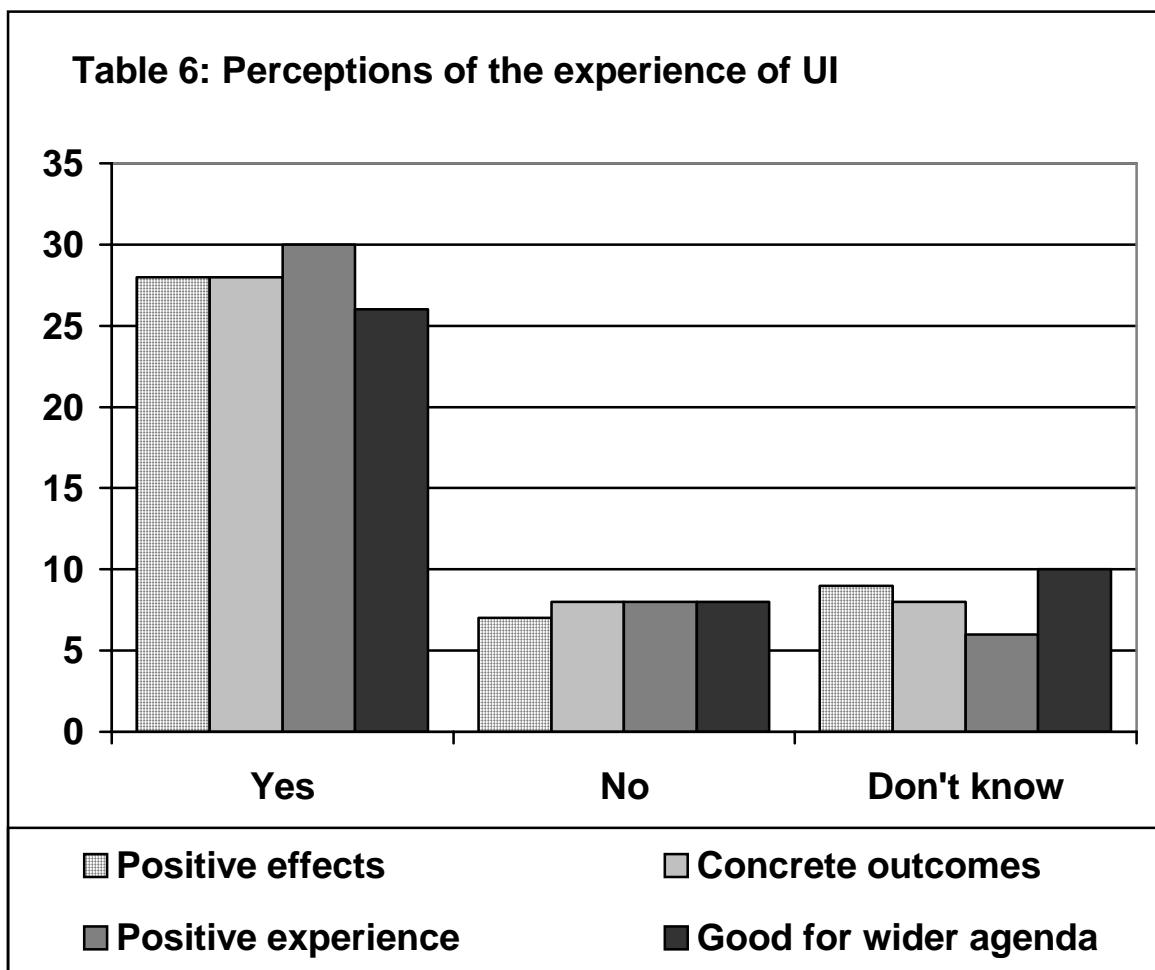
A closer look at the comments made reveals more detail.

Has the project had a positive effect on people in your area?

Positive effects cited by respondents fell into four main areas. These were:

- improved skills and confidence for disabled people (6)
- improvements in services or awareness of existing services (8)
- more power and control in the hands of disabled people (4)

- better awareness of Disability Equality issues and UI on the part of professionals (6)

The general pattern of beneficial effects reported involved the development of more appropriate services through the greater input or control of disabled people. However, seven projects (16%) reported no positive effects or else struggled hard to find something constructive to say:

> *"Officers are being asked to do consultations without understanding their purpose or the nature of sectors outside their own."*
>
> *"Reasonably successful. Difficult to measure effect on culture of LA workers, subtle."*

Have there been any concrete outcomes from the projects surveyed?

A number of organisations mentioned improvements in support and services for independent living. One respondent who had taken part in a Best Value review of day care services was able to list four concrete outcomes:

> *"A Day Centre 'warehouse' run by a large charity under contract will close. The service will re-tender with a new specification 'to more appropriately reflect the varying needs of service users'.*
>
> *A job specification is being prepared for a Community Resources Development Officer, and It is acknowledged that [the reporting organisation] would be eligible to bid to run parts of the alternative provisions".*

However, this was the exception rather than the rule, and most outcomes were more intangible.

Overall, was this project a positive or negative experience for your organisation?

Again, most projects were viewed as a positive experience, one just commented: "they listened". Several stressed the quality of the experience when disabled people had taken the lead role:

> *"Positive: this is how good it can be when disabled people's organisations take the lead and manage the process."*
>
> *"Because it was user controlled, we got this right."*

Two respondents said that because of UI in a specific project, they had benefited by increased resourcing:

> *"Led to ongoing funding for our organisation…"*
>
> *"Now have a CIL providing a range of services that we didn't have before."*

Do you believe that this involvement promoted disabled people's rights or contributed to the wider agenda?

Respondents found it more difficult to reply to this question, with a higher level of "don't knows". This could be because it takes a long time before changes to policies are visible, or because organisations have not been in a position to monitor the wider effects in the long term. One comment reflected the general view among positive responses:

> *"Disabled people's agenda more fully represented within local authority priorities."*

General comments

Respondents were given the opportunity to consider and comment on their overall experiences, and although the data would seem to imply that

UI is generally viewed positively by the organisations taking part, these respondents express somewhat ambiguous opinions, which need further exploration and analysis.

> *"My experience working within this organisation (name removed) and others over the last 10 years is that the availability of effective independent advocacy is more able to influence a change in culture than most user consultation exercises."*

> *"What usually tends to happen is that a small core group of disabled people become involved in a range of different initiatives and the real voice and experiences of disabled people then become muted."*

> *"Lack of resources and inaccessible structures most often mean that consultation becomes ineffective and people become tired of being asked and seeing that nothing changes."*

> *"We are asked regularly to 'supply' disabled people for research, UI etc. We are a small organisation and can't 'supply' people at the level required. Also people have their own lives and do not just get involved in UI unless it's going to make a difference to them."*

Several organisations who were sent surveys telephoned to apologise for not being able to take part in the exercise for various reasons, but offered a number of comments generally about UI.

> *"Sorry we can't help with this . . . there's a deadline on a large piece of consultation we are actively involved with around the Fairer Charging policies . . . it's our very existence and standards of living that are at stake . . .it's taking up all our energy and resources but that's what we (organisations of disabled people) should be doing. Reserve our energies for the really important battles."*

> *"Our experience of UI has been mixed.   When we have been invited to be involved in a lead way or form a partnership, it has usually*

meant processes went well and improvements or policies are significantly influenced by our active involvement.   However, things can go the other way too and sometimes we are just used as 'fodder' or to show that an LA can tick the box saying 'done' UI and that's all they want us for – I think we have to be really careful."

KEY POINTS

In general, projects that involved partnership or a lead role for disability organisations gave rise to positive scores and benefits, including

- improved skills and confidence
- improvements in services
- more power for disabled people
- better awareness among professionals
- disabled people's agenda gained a higher profile in LA decision making

By contrast, projects that offered less control were a more negative experience. Points mentioned were:

- poor facilitation
- tokenism
- attempts to manipulate outcomes

Some respondents expressed personal views, including:

- independent advocacy is more effective than UI
- the same small group tends to be consulted every time and masks real views
- lack of implementation leads to disillusionment and lost motivation

- disability organisations must focus their efforts on improving people's lives
- we are sometimes just used so that the box marked UI can be ticked

1.1.1.18.5 Chapter six: Analysis of research results

This chapter provides an analysis of a number of significant issues and themes which have emerged from the results of both the fieldwork presented in the previous two chapters and from the wider context of the literature and policy review in chapter two.

EMERGING THEMES

The range of UI and satisfaction with processes

This small-scale study reveals that, over the past five years, organisations of disabled people and their members have been involved in a wide variety of UI activities, with a number of different agencies and at varying levels of participation. However, the primary focus of disabled people's attention remains on their relationships with SSDs and the provision of essential support arrangements such as 'home care' and direct payment schemes.

> *"Through organised co-ordinated working with Social Services Departments (SSDs) we have been able to provide a level of consumer involvement that is valued, user-led and consistent. However, to date working with Primary Care Trusts has not been so successful and we still have some attitudes to change." (survey respondent)*

A move forward

Studies included in the literature review (chapter two) highlighted the efficacy of UI when quality partnerships are built. Others stress that UI is not merely useful, but "should be regarded as a civil rights issue" (Morris, cited in d'Aboville, 1995:4). Following the incorporation of UI into

legislation, in recent years there has been a small explosion in the number of such exercises.

The perception that UI is a valuable activity (when properly done) was reflected by the majority of responses gathered from fieldwork.

> *"This shows how good it can be when disabled people take the lead." "For once there was real change as a result of UI." (survey respondents)*

However, some aspects of the current 'state' of UI highlighted by this study are more negative.

Consultation fatigue

Consultation or research fatigue "occurs where disabled people are constantly being asked for their views in all sorts of surveys, many of which have little or no impact on their lives" (Morgan, Barnes & Mercer, 2001,2: 9). Throughout this study, consultation fatigue was raised as an issue by the majority of respondents to the surveys and from the participants in the focus group and interviews.

Representatives of organisations and individuals felt there were too many demands made on them to take part in UI:

> *"We are asked regularly to 'supply' disabled people for research, UI etc . . . people have their own lives and do not just get involved in UI unless it's going to make a difference to them." (survey respondent)*

Another respondent commented that the same people tended to get consulted repeatedly: this may be adding to the feeling that there is too much UI.

Disillusionment

In addition to the excess amount of UI, the lack of consequent tangible benefits appears to have led to a degree of cynicism. Only 12 of the 44 UI exercises surveyed had yielded a positive outcome that could be described as tangible. One respondent commented:

> *"Lack of resources and inaccessible structures most often mean that consultation becomes ineffective and people become tired of being asked and seeing that nothing changes." (survey respondent)*

Tokenism and being 'used'

Worse than a perceived lack of benefit was the feeling from some respondents that UI was often a tokenistic activity.

> *"We are just used as 'fodder' or to show that an LA can tick the box saying 'done' UI and that's all they want us for." (survey respondent)*

As the literature review revealed (Davis, Ellis & Rummery, 1998), there can be a tendency for social workers (and others) to pursue their own agenda rather than engaging with the expressed wishes of their 'clients'. Participants in both of the projects examined in depth during this study felt that their work had been to some extent misused or distorted. Survey respondents also expressed misgivings:

> *"Officers are being required to conduct statutory consultations without understanding their purpose or the nature of sectors outside their own."*

Scepticism and selectivity

As a consequence of consultation fatigue and a degree of scepticism regarding agencies' motivation, it appears that disabled people as

service users are becoming much more selective than in the past in deciding to whom they will give their views and in which UI activities they will agree to participate.

"I think we get used too much, so I am very choosy about who I give my views to." (Tim, BV interviewee)

Organisations are beginning to set priorities which reflect perceptions of which project is likely to be of most benefit to them or their cause.

Empowerment and obstruction

Many participants in this study reported considerable benefits in terms of personal empowerment and skills learnt:

"I personally got a lot from it. I felt much more confident both in myself and what I could do." *(Sian, BV interviewee)*

Sometimes this empowerment took the form of knowing better how to play the game next time:

"We will be better prepared and know what questions to ask before we do anything like this again!"   (SA focus group)

However, the limited nature of this empowerment becomes evident when confronted with systematic attitudinal barriers. User research groups who took part in this study had experienced significant levels of obstruction from some staff, on one occasion requiring the intervention of the Director of Social Services.

Facilitation and inclusion

When support, training and access needs are met, the benefits of UI to both service users and providers have been shown to be significant (Lindow, 1999). Satisfaction with facilitation and ability to influence the

conduct of projects was rated as average or above for 34 of the 44 projects surveyed for this study. Exceptions occurred where facilitation was organised exclusively by professionals or by inexperienced non-disabled people from the voluntary sector. Some disabled service users themselves frankly identified their own initial lack of understanding of the needs of others. They also emphasised that effective involvement needs commitment, not only of resources, but also of time.

Inclusion is identified as an area that needs attention, both with regard to disabled people from minority ethnic communities and to the wider community of unpoliticised disabled people.

> *"What usually tends to happen is that a small core group of disabled people become involved in a range of different initiatives and the real voice and experiences of disabled people then become muted."*

1.1.1.18.6 Chapter seven: Conclusion

1.1.1.19   This final chapter draws on the themes and issues outlined in Chapter Six to present an evaluation of the current UI picture and indicate some lessons for its future development.

1.1.1.20

INCREASING INFLUENCE ON POLICY

The success of disabled people's influence on policy depends on a number of factors: the negotiating skills and strengths of organisations of disabled people, the extent to which they have access to resources and conduits of power alongside the readiness of social and political institutions to change (Drake, 1999). The relinquishing of power over welfare and other related services to disabled people is fundamental to any change.

As a result of disabled people's redefinition of their situation in terms of human rights and equality, together with their increased visibility in society, they now have a higher political profile than in the past (Drake, 1999). There is evidence that disabled people are engaging with the processes and systems of government and further developing their expertise in campaigning, advocacy and self-organisation.

Furthermore, by adopting a pragmatic approach in their attempts to influence policy, it has been possible for disabled people and their organisations to effect changes, particularly in local health and social services policies. Although some of these have been relatively small changes at local levels, others have been more visible. For example, as

a consequence of the success of the Direct Payments legislation and the growth of the Independent Living Movement, disabled people once 'perceived as passive recipients of services' (Begum & Fletcher, 1995; Wood, 1991) now have greater choice and control over how their support needs are met and are increasingly able to demonstrate that they are demanding consumers of quality services in other areas.

1.1.1.21

1.1.1.22   THE PRESENT AND FUTURE OF USER INVOLVEMENT

Is UI a worthwhile activity?

It is difficult to quantify the impact that disabled people's involvement has had on changing policy or services, particularly where there appears to be little hard evidence on which to base any assessment (Campbell & Oliver, 1996; Drake, 1999). However, it may be possible to use Marx and Adams' (1994) and Campbell and Oliver's (1996) criteria for gauging the progress of (new) social movements as a framework with which to evaluate the effectiveness of disabled people's activity within UI.

Marx and Adam put an emphasis on concrete change: political, economic, legislative, attitudinal and behavioural. Although this study found that only a minority of projects resulted in tangible change, there was a feeling that such change was worth the effort:

> *"We now have a CIL providing a range of services." "For once there was real change as result of UI!!" (survey respondents)*

It should also be noted that many of the projects surveyed were recent or ongoing, and participants were still in the process of pressing for implementation.

Campbell and Oliver (1996) present standards which are more difficult to use as a measure: the raising of consciousness and empowerment of disabled people, the raising of disability issues, the promotion of disability as a civil rights issue. However, these aspects are fundamental to the emancipation of disabled people. Participants in this study were perhaps most enthusiastic about personal empowerment as a benefit of UI:

> *"Participating users gain confidence and knowledge." "Increased confidence of disabled people." (survey respondents)*

Although some have questioned the reach of UI into the community, it seems undoubted that UI does draw in those who were previously uninvolved and raises their consciousness of inequality:

> *"I have became more aware that DP users and disabled people generally are expected to be accountable all of the time . . . which wouldn't be accepted by non disabled people." (Tim, BV interviewee)*

With regard to raising disability issues, this study looked primarily at local initiatives. At this level most organisations felt that their efforts had been effective. One commented:

> *"Disabled people's agenda is more fully represented within local authority priorities." (survey respondent)*

Some organisations reported "*increased Social Services awareness of disability issues"* but most found it difficult to quantify any benefit from their UI activities in terms of civil rights or the wider agenda. In practice, as a result of legislation, local authorities are now obliged to consult with users. However, this appears to be regarded by some as an imposition, and this study contains evidence of a continuing "us and them" culture.

Previous studies have emphasised the importance of breaking down barriers and working co-operatively, including a willingness to change, when developing responsive services.

Scepticism, selectivity and the evolution of UI

The consultation fatigue, disillusionment and scepticism found during this study ostensibly give cause for concern. Service users are aware that professionals are obliged to consult them and feel themselves used to fulfil this requirement.

Furthermore, when disabled people's experience is that the value of UI is doubtful and that the outcomes have the potential to become distorted or the findings to be manipulated to fulfil another party's agenda, it is likely that they are going to be even more reluctant to enter into dialogue, or worse, will refuse to take part.   As it is, there is evidence of increasing selectivity on the part of disabled service users and organisations.

UI is still a relatively recent activity, certainly in the amount that is currently being practised. It is perhaps inevitable and positive that disabled people re-examine the role they play within it. Some already impose their own standards:

> *"Disabled people are involved in design and application of the methodology on all the UI we do." (survey respondent)*

Control was seen to be key by many disabled people's organisations: they were noticeably more satisfied with the conduct of exercises in which they had taken a leading role, and particularly when they had been the initiators. This is, perhaps, a result to be expected, but one

respondent highlighted the reason for the success of such self-initiated
UI:

> *"Then there is an expectation that [members'] views will be acted*
> *upon as the organisation is accountable to its users/members."*

Observations like these, drawn from practical experience in the current
'UI industry', are contributing to the formulation of 'rules of engagement'.
It is to be expected that these principles will solidify and perhaps sharpen
disabled people's involvement, particularly if they are disseminated to
new or less experienced groups.

Building alliances and funding

UI tends to draw disabled people into partnerships with service
providers. There are a number of potential hazards in building alliances
with statutory and charitable organisations: the interviewees and survey
respondents who took part in this study expressed their concerns in this
regard. Campaigning for changes to the way society is structured and for
equal rights, was the mobilising force behind the emergence of the
disability movement. Recent studies demonstrate that although there
may be differing views on the shape of such activities, this remains a key
function for the majority of organisations of disabled people (Barnes,
Morgan & Mercer, 2001).

Historically, organisations of disabled people have derived the major part
of their funding from local authorities, usually via social services
departments (Barnes, Mercer, Morgan, 2001) and as a consequence are
dependent to a large extent, on maintaining harmonious relationships
with them.

More recently the National Lottery and 'acceptable' charities such as Comic Relief have awarded grants to support the work of user groups, which (to a small extent) has reduced reliance on LAs. However the nature of this type of funding involves fixed duration and designation for specified projects. As a consequence of the uncertainties surrounding the resourcing of organisations of disabled people and therefore UI, it is perhaps inevitable that disabled people have tackled issues in a 'piecemeal' way, most often at local levels. This may be a factor contributing to the difficulty of assessing the impact that disabled people's involvement has had on influencing policies and services. Until alternative forms of funding are made available to promote citizenship participation (as proposed for funding of political parties) there will always remain an imbalance of power and a limit as to how far disabled people can effect changes through UI alone.

For the past decade disability theorists have criticised the funding of research, arguing that those who decide on the subjects to be studied or who provide funding, and the political or other interests these parties may hold, often influence the research process and its outcomes (Oliver, 1992). Similarly, the validity of a large number of UI projects must be subject to question when the funding body is both the subject of the consultation and controls the purse-strings of the organisations which are conducting or contributing to the project.

Facilitating UI

The review of literature demonstrates that, despite pockets of good practice, many commissioners are still unaware of the basic aspects of facilitating UI or have little awareness of the cultural and religious needs of minority ethnic service users: this was reflected in the current study.

There is a need, therefore, for more effort and resources to be made available to reach out to marginalised groups and to provide support and training to enable service users to play a more meaningful role in decision-making processes.

The future for disabled people's involvement

If UI is to be viewed as a valuable resource and worthwhile activity, it will require a commitment from all concerned, an investment in time and resources and it must be relevant to the lives and needs of all disabled people. Furthermore, the future for UI has to be one of equal partnerships between disabled people and the agencies and other professionals involved. Only when the balance of power surrounding services required by disabled people is changed will dependency in this context be reduced and disabling barriers to full citizenship be removed.

The wider picture

While there have been a number of advances because of UI, it is important to remember that user involvement is a means to an end and not an end in itself (Oliver & Campbell, 1996). This end is the emancipation of disabled people through full human and civil rights, and the right to participate in society on equal terms with others.

The experience of the last few decades appears to teach us that the emancipation of disabled people will not come about by reformist methods alone, but through a combination of methods, some of them revolutionary. These tactics may include direct action in the form of civil disobedience to confront, challenge and raise awareness of the issues; campaigning, boycotting and lobbying at different levels; underpinned by academic research, evidence and argument. Ultimately their success will

lie in the strength and solidarity of a disability movement which is inclusive and is relevant to all.

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Appendix 1: Questions used for interviews/focus group

INTERVIEW QUESTIONS

1. What research or consultation have you done before?

2. Do you think it made a difference? How did you fell about it? Good, bad?

3. Tell me about the recent study you took part in
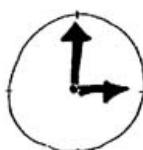
4. What did you do in this project/study?
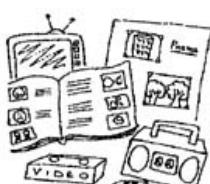
5. When were you involved – beginning, middle, end?
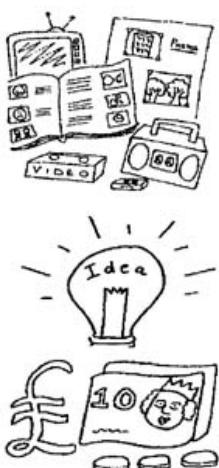
6. Did you have enough information?

7. Whose idea was it to do the study/project?
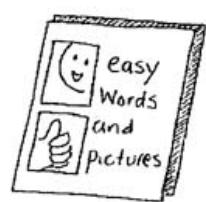
8. Were you paid for your time and for travel?

9. Were you listened to by other people?

10. Did anything stop you from taking part?

A2

11. Did you have support to take part?
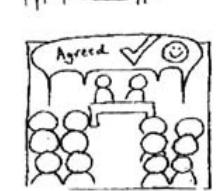
12. Did you have any training to help you do things?
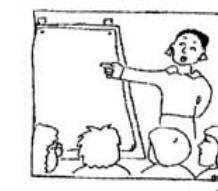
13. Have you learnt new skills now?

14. Do you think it has made you fell more confident or not made any difference?

15. Anything else?

16. Do you think it was good use of your time?

17. Could anything have been done better do you think?   What?

18. Would you do it again – be involved?
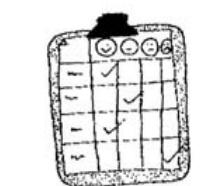
19. What do you want to happen now with the results of your hard work - report/involvement?

20. Anything I have forgotten to ask you want to tell me.

2

Appendix 2: List of organisations surveyed

Surveys were sent via email and post to:

Access Ability Lothian
Barking and Dagenham Centre for Independent Living *
Barnet Coalition for Independent Living
Cardiff and Vale Coalition of Disabled People
Centre for Independent Living in Glasgow (CILiG) *
Derbyshire Coalition for Inclusive Living (DCIL) *
Disability Action North East (DANE)
Disability Wales
Greenwich Association of Disabled People's Centre for Independent Living (GAD)
HAFAD *
Hampshire Centre for Independent Living
Herefordshire Centre for Independent Living
Ideal for All Ltd (Sandwell Disability Living Centre)
Independent Living Alternatives *
Interdependent Fellowship (The IF Group)
Independent Living Association West Sussex (ILA) *
Lancaster DISC (PDSI) *
Leeds Centre for Integrated Living *
Leicestershire Centre for Intergrated Living
Living Independently in Gloucestershire *
Lothian Centre for Integrated Living (LCIL)
Southampton Centre for Independent Living *
West of England Centre for Integrated Living (WECIL)
Wiltshire & Swindon Users Network *

* organisations who returned surveys

Appendix 3: Letter and survey form

Dear

I am writing to ask for your assistance with a research project I am working on for a Masters Degree in Disability Studies with Leeds University, under the supervision of Drs Colin Barnes and Geoff Mercer.

One focus of the early disability rights movement in the sixties and seventies was to demand a voice for disabled people in the formation of policy that affects their lives. Policy makers are now required to take into account the views of users: do current methods of user involvement fulfil or dissipate the vision of disability rights campaigners?

The aims of my research project are to evaluate disabled people's experiences of being involved in research and consultation projects, and to assess (from disabled people's perspective), the impact of user involvement practices over the past two decades by identifying tangible signs of change.

To address the specific aims of this project, this study will employ the following approaches:

To address the question of UI's efficacy as a means of gathering and communicating disabled people's perspective, a detailed examination of two recent studies will be undertaken.   This qualitative exercise will attempt to establish whether UI is perceived as a worthwhile and successful activity or otherwise for the individuals concerned.

To assess whether, within the relatively short lifetime of UI as a part of local policy making, concrete outcomes have been delivered, a quantitative postal/email survey will be undertaken with organisations OF disabled people

I would be grateful if you could spare some time to complete the attached/enclosed questionnaire and return it to me either by email at ….or by post to the address at the top of this page, by **Tuesday 9th July** or sooner.

All of the information will be treated with sensitivity and will not be attributed to any individual or organisation. If you would like a summary of the final study when its available, I am happy to send you one –please indicate so in the space provided on the form.

Thank you in advance for your assistance.

A SURVEY OF SERVICE USER INVOLVEMENT

Please answer as many of the questions as possible, and return to Angie Carmichael as soon as possible, final deadline is **Tuesday 9th July** 2002. Thank you very much for your time.

Date survey completed_____

1   Organisation Details

Name of organisation	
Address	
Telephone no	
Email/fax no	
Name of person completing survey (for contact purposes only)	
Position within the organisation (if any) of person completing the survey:	

2   Previous UI

Please list the projects your organisation has been involved with in the past five years which have included any form of user involvement:

Reference letter	Name of project	Year of completion
A		
B		
C		
D		
E		
F		

3   Questions based on projects listed above (section 2)

Please complete the following details as best you can, using a tick or by giving brief details as appropriate:

	PROJECT A (from table in section 2)
1	What was the nature of your organisation's involvement in this project? (tick ✓) Lead organisation ☐ Partner with SSD or other ☐ Supplied participants ☐ Other ☐ (please give details) _____
2	Was your organisation satisfied with the way project was carried out? (eg were access needs met, did participants feel they were listened to, were they able to influence the way the project was carried out?) Please rate your satisfaction by ticking ✓ number (1= low, 5= high) 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ Do you have any comments on the conduct of the project?
3	Has the project had positive effects on the lives of disabled people in your area? (please tick ✓ as appropriate) Yes ☐ No ☐ Don't know ☐ If yes, please give details
4	Have there been any concrete outcomes from this project (i.e. changes in policy or practice by service providers, more resources, more opportunities for disabled people's involvement)? Yes ☐ No ☐ Don't know ☐ If yes, what are they?
5	Overall, was this project a positive or negative experience for your organisation? Yes ☐ No ☐ Don't know ☐ Any other comments? **Section 2:**
6	Do you believe that this involvement promoted disabled people's rights or contributed to the wider agenda? Yes ☐ No ☐ Don't know ☐

4   Do you have any other comments to add about your/your organisation's experiences of taking part in service user consultation/involvement activities?

Thank you very much for taking the time to complete this survey. Please return it to Angie Carmicheal by post to 4 Rudmore Park, newbridge, Bath BA1 3JA or by email to angie@sparringpartners.co.uk

PLEASE RETURN AS SOON AS POSSIBLE, LATEST BY TUESDAY 9TH JULY.

If you would like a copy of the report summary, please indicate below and the address you would like it sent to.

Yes, I would like a copy of the report summary when available ☐

[NOTE: For section 3 a separate sheet was provided for each of projects A to F.]