

Measuring Disablement in Society: Working Paper 5  
Measuring Disabled People's  
Involvement in Local Planning

Nasa Begum and Gerry Zarb, 1996

## **Introduction**

This report is one of a series of Working Papers based on the '*Measuring Disablement in Society*' (MDS) project being undertaken by researchers at the Policy Studies Institute with funding from the Economic and Social Research Council. Other Working Papers cover topics including transport provision for disabled people, accessible environments, employment, and the Citizens Charter.

This paper will explore the background to the development of user involvement, discuss what is meant by user involvement and summarise the key issues to emerge from the literature. It will then explore how the spectrum of user involvement works and consider some of the barriers to disabled people's involvement in user involvement. Finally, the paper outlines the key issues for measuring the effectiveness of disabled people's involvement, both in terms of outcomes and process.

## **The importance of user involvement**

The involvement of people in shaping the political, economic and social environment they live in is a basic premise of democratic societies. Theoretically everyone can participate in decision-making processes, either at an individual level or on a collective basis. However, in practice it can be much more difficult to participate as complex organisational structures, bureaucratic procedures and professional territorialism often prove to be major obstacles.

Research and literature highlighting discrimination faced by disabled people in Britain (Barnes, 1991; Swain et al, 1994; Zarb, 1995) suggests that one of the key factors contributing to disabled people's marginalisation and oppression in society, is the range of barriers that are confronted when trying to take part in decision-making processes at a local, regional or national level. In addition, a 'welfare' oriented approach to meeting the needs of disabled people means that often disabled people are not only denied the right to participate in society, but more fundamentally, have very little control over their own lives.

The research and literature on discrimination also highlights that existing public services often fail to meet their needs. It has been suggested that one of the main

reasons for this is that disabled people have often been excluded from being actively involved in planning or designing these services.

Current interest in 'user involvement', consumerism and participation highlights a particularly important area of debate for disabled people, because it potentially provides a benchmark for measuring the extent to which disabled people are excluded from both society, and from exercising control over their own lives. Measuring disabled people's involvement in local planning is crucial for determining the level at which they are participating in the social political and economic life of the community.

### ***Community development and user involvement***

Community development work, popular in the late 1970s and early 1980s, may be regarded as an earlier version of user involvement. The common concern of both approaches was to bring about change by reaching out to and involving local people in the process of change. However, the emphasis of community development was on collective rather than individual action.

Twelvetrees (1982) identifies three approaches to community development:

- i) community development: creating and servicing community organisations bringing people together to identify their needs and work on them;
- ii) political action: a class-based approach, organising and linking working class organisations and campaigns;
- iii) social planning: promoting joint action between voluntary and community organisations and the local state to change and improve services.

In addition, Peter Wilmott suggests that most forms of community initiative fall into four categories - depending on how they are initiated and controlled.

- X *Neighbourhood life* - daily activities taking place without any formal organisation in local communities.
- X *Community action* (bottom-up)- indigenous activities organised by local people.
- X *Community development* (top-down or intermediate) - efforts involving

community workers, other professionals and enthusiasts.

- X *Implementation of official community policies* (top-down) - measures by institutions to complement policies and promote collaboration (Wilmott, 1989: 25).

The main difference between community development initiatives and user involvement can be is a question of focus. The former tends to assume more collective action, whereas the latter emphasises individual action and exercising one's rights and responsibilities as a citizen to whom services are accountable. In reality the distinction between community initiatives and user involvement may not be as clear cut as one might think for three main reasons:

- i) the language of user involvement has been used interchangeably to refer to the development of community groups as well as to eliciting the views of an individual user through some form of consultation exercise, or enabling individual users to participate in a planning mechanism.
- ii) user involvement may be perceived as simply another form of community work, which has been endorsed through official government policy, to encourage a more collaborative and participatory society.
- iii) the community work approach, which encourages grass roots initiatives, is often a key component to enabling users to participate in the planning and delivery of services.

Although the intention behind a lot of the community involvement initiatives was to encourage more participatory approaches, it is unclear how much was being shaped by 'professional community workers' and how much the priorities, decisions and action were determined by local people. Croft and Beresford (1992) point out that tensions have emerged in community development between:

- X *change and involvement* - the two do not necessarily go hand in hand, as involving people can slow down the process of change, and make it much more difficult to achieve tangible results;
- X *rhetorical and real scale involvement* - while the rhetoric is of large scale involvement - the reality is more often one of limited numbers. Broadbased involvement may not even be a primary issue on the hard pressed community worker's agenda
- X *enabling and organising* - present two potentially conflicting roles. While a

supportive approach seems consistent with enabling and extending people's involvement, an organising one suggests a more one-sided relationship with leaders and followers. This may be a way of creating more 'community' or 'user leaders', but whether that is the same as increasing people's participation remains open to question (1992:30).

The concerns emerging from a community development perspective provide a foundation for understanding the current discussions about user involvement. Indeed in many ways the same, or similar, tensions can be witnessed when considering the participation of individuals and groups, in the planning and delivery of services.

### **The current context**

What is user involvement?

The notion of user involvement formally emerged on the social policy agenda early in the 1980s, as a result of the National Health Service and Community Care reforms. Yet the philosophy and principles underpinning user involvement are also clearly linked with wider debates about community development, citizenship, consumerism, participation, empowerment and accountability.

The concept of citizenship and individuals having a greater involvement in the society that they live in has attracted growing enthusiasm within the social policy arena ( Croft & Beresford 1989, Oliver 199?). There is an expectation that individuals will not rely on the state to take control over the provision of goods and services, but as individuals, or rather 'citizens', people will take on responsibility for making decisions about goods and services available. This may be through the operation of market forces, or by participating in the design and delivery of services which affect people's lives.

Successive Conservative Governments have emphasised a market-oriented approach to the provision of public goods and services. As a result, public sector provision has been through a process of major reform creating an environment where users are perceived as 'consumers' or 'customers' to whom the public sector is accountable. Thus information is produced in the form of charters, league tables and other performance indicators enabling consumers to make their own decisions about how well services are performing, or whether they wish to opt for one type

of provision (such as a particular school) or another. (See MDS working paper on the Citizen's Charter).

Clarke and Stewart (1987) describe a new approach to the provision of public sector services known as 'public service orientation, where the emphasis is both on the customer for whom the service is provided and on the citizen to whom the authority is accountable. In part the rationale for this may be understood by post-modernist theories of trying to move away from universalist provision to recognising diversity and catering for people's different needs (Croft, S & Beresford, P 1992). Equally, it can be argued that the public world of consumerism, with its increased emphasis on citizenship, is attributable to a concern to move towards a more individualistic society where people are seen to be responsible for participating in a democracy, rather than relying on others to represent their interests. This is something that disabled people in Britain particularly welcome, as one of the major criticisms of public sector provision is that disabled people have traditionally been perceived as 'passive recipients' of welfare services rather than active citizens who wish to exercise choice and control over their own lives (Begum & Fletcher 1995; Wood 1991).

User participation and user involvement can be regarded as attempts to directly involve people in the political, administrative and other processes that affect their lives. User involvement tends to focus particularly on enabling people who use services (most often associated with welfare services) to plan and deliver the services they require.

### **What is meant by user involvement?**

The term user involvement is still often applied to almost anything which involves members of the public in the planning or delivery of services. There is a lack of clarity which makes it difficult to evaluate how user involvement might work in practice. It is useful to briefly explore how the term user involvement is being defined by disabled people and how it is being employed in practice.

User involvement has been defined as, *>disabled people being involved in many different ways in planning, implementing and evaluating services* (Begum & Fletcher 1995:20). As most disabled people are likely to use some form of service during their life, the term user refers to all disabled people.

Jenny Morris points out that user involvement needs to go beyond narrow notions of disabled people's needs, and be regarded as a civil and human rights issue:

*>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. Unless service users are fully involved in every stage - from planning through to service delivery - their human rights will not be protected nor will their civil rights be promoted. User involvement is not an optional extra; it is absolutely essential to the proper implementation of community care (cited in d'Aboville 1995:4).*

For disabled people user involvement is about promoting democracy, empowerment and equity. Whilst for policy makers and practitioners user involvement tends to be much more about promoting consumerism and inviting users to influence the design and delivery of services (Beresford and Campbell, 1994). The hub of the difference between disabled people's perspective and that of service agencies appears to rest upon the whole issue of power, and who holds decision-making powers. There has been a growing interest in moving away from a 'them and us' scenario between disabled people and service agencies; therefore the notion of 'partnership' working has become increasingly popular. Partnership working usually refers to situations where disabled people and service agencies work together to plan and deliver services. However for a partnership to work successfully both parties need equal power. Beresford and Croft point out that it is not possible to involve users without sharing power. Disabled people and people in service agencies do not enter into a 'partnership working arrangement' on equal terms. The historical and cultural reality of many service agencies is such that disabled people start off at a disadvantage because their skills, knowledge and experience are different from those of people who work within service agencies, and as such are not recognised (Croft & Beresford, 1990).

User involvement is about enabling disabled people through the provision of practical support, training, access to resources and sharing decision-making powers, to participate in society. The concept of *empowerment* is central to the debate about user involvement, however it is important to distinguish between user involvement and empowerment. The latter is about actually equipping disabled people to be able to take control so that they have the knowledge, skills and power to make decisions and act upon them; whereas the former, user involvement, tends to be much more about inviting disabled people to participate in the planning or delivery of services. In practice user involvement and empowerment are part of the same equation, because without equipping disabled people to have the knowledge, experience and power to make decisions and act upon them, user involvement is likely to be quite limited in terms of both its purpose and outcomes.

## Spectrum of User involvement

User involvement can take many different forms and works at both an individual, and a collective, level. There is a spectrum of user involvement ranging from the provision of information at one end, to offering disabled people control over budgets and the delivery of services at the other end. Jenny Morris refers to the spectrum of user involvement as a form of currency, she explains: "*user involvement is a currency - it's what users have instead of money to ensure that they get what they need. In this sense, there is not just one coin which achieves the result of appropriate, efficient services, but a number of different coins that we use to achieve this goal. Some coins have greater purchasing power than others but they all have their place*" (d'Aboville, 1995:2).

Often the spectrum of user involvement is not recognised, and people assume that a particular consultation exercise or meeting, is sufficient to meet any requirements to involve users. In order to measure the effectiveness of user involvement it is useful to explore the spectrum of user involvement.

The spectrum of user involvement is shaped by the degree of power and control disabled people have over the decision-making processes and the delivery of services.

*Information Provision* > *Consultation Individual/Group* > *Joint Working* > *Delegated Control*

### Information Provision

The old cliché 'knowledge is power' is particularly appropriate when considering how the provision of information forms part of the spectrum of user involvement. Access to information in an appropriate format is necessary to enable people to make decisions about their lives and what they want in terms of the community and society that they live in. Without information people are not able to even begin to make decisions or participate in the planning and delivery of services.

Information may take the form of formal notices in a newspaper (e.g. planning notices, or the publication of league tables), or it may take the form of interactive videos, leaflets and information stalls in public places or within the private domain of one's home. In order for disabled people to be able to use information effectively it is essential that it is produced in formats such as Braille, tape, large print, pictures, community languages, signed video tapes and transmitted through sign

language interpreters and word of mouth.

Producing information in accessible formats is an important part of the process of involving disabled people. Nevertheless, the provision of information on its own is limited, if information is not disseminated to places where disabled people can access it (Moore N, 1995). Also, the provision of information will not in itself generate well informed consumers if that information cannot be understood easily, or acted upon easily. For example, people cannot make a decision about which school to send their child if educational league tables and other literature do not provide details about facilities for disabled people, or the number of disabled children in integrated classes. Equally, disabled parents need information about how accessible the school is.

The large number of charters within the public sector represent a shift towards user involvement, by encouraging individuals to be better informed about what they can expect and what can be done if the standards laid down are not met, e.g. lodge a complaint. As consumers and citizens, people are expected to make decisions and choices based on the information that they receive. All too often disabled people have not been able to participate in society or make decisions about their own lives because they have not had access to the information that they required. In a consumer-oriented society information provision has become a crucial tool, however it is important to recognise that a lot of the information provided is very selective. For example, people may have access to certain information within their health and social services records, but because of restrictions on what information can be given (such as something written by a third party), in effect it means that disabled people can only make decisions on the limited information that they allowed access to. Similarly information produced by service providers or other agencies may be so concerned about presenting a good public image that it may not give an accurate all round picture about the organisation or service.

Information is extremely important as the first rung on the ladder of user involvement. However, if information is the only form of involvement available disabled people are limited to a fairly passive role, in that whilst they can make decisions based on the information received, there is very little that they can do to bring about significant change. The ability to exercise power is restricted to a very individual and reactive level, where, as a consumer of services or as a citizen, a disabled person may choose a particular course of action rather than another. For example, disabled people may choose to vote for a certain political party because of the information they have received about the different politicians.

## **Consultation**

Information provision and consultation are often seen as being synonymous with each other. However, technically consultation should be a more active form of user involvement. Rather than users being perceived as some form of sponge that soaks up information and then chooses what to do with it, consultation gives disabled people a role in influencing the decisions that others make.

Consultation is essentially about listening to the consumers or users of services and trying to base decisions upon opinions expressed. In recognition of the fact that disabled people should have a greater role to play in the decisions that effect their lives, consultation has become a popular and widespread form of user involvement (Lindow V & Morris J, 1995). All too often, however decisions are made about the nature of services and about different aspects of community life, without actively involving disabled people in the decision-making process.

The expertise of disabled people at an individual or collective level was never really recognised before the 1980s. Since then, the disabled people's movement has grown rapidly, and there is increasing pressure from disabled people to no longer accept exclusion from the decision making process in economic, social and political aspects of their own lives. An effect of this is that consultation mechanisms have become a central plank in different areas of social policy, such as housing, education, transport, health and social services (Lindow V & Morris J, 1995).

Consultation can be defined as >seeking advice or information from disabled people (d'Aboville 1995). It can work at an individual level, such as asking a disabled person their view on a particular issue(s).

Equally, consultation can be at a group level, working with disabled people on a collective basis to ascertain their views and ideas on certain issues. It is useful to explore both forms of consultation, as each raise specific issues and questions in terms of how effectively they encourage the involvement of disabled people. However, in discussing consultation, it is important to bear in mind that on the whole power remains with the agency or organisation who is embarking upon the consultation. The latter are merely conferring with disabled people to seek their opinions and advice, and there is no guarantee that the ideas expressed by disabled people will be acted upon.

### ***Individual consultation***

Individual consultation is a daily activity, which is happening all the time when people are asking others questions or seeking advice. In addition, a medical model

of disability means that, as statutory agencies often act as gatekeepers to essential resources, there is often a regular process of individual consultation, in the form of official assessments, that disabled people have to go through to access services and resources.

Consultation at an individual level encompasses many different techniques including research. It covers methods such as qualitative interviews, large scale surveys, individual assessments, discussions, phone-ins and so on. Basically individual consultations means working with a single disabled person. The consequence of this is that the agency or individual consulting receives the views, ideas, preferences and opinions of a single disabled person.

Individual consultation is valuable in terms of enabling service users to express their own needs and suggest how these needs can be met, or to find out the potential diversity of opinions on a particular issue. However it is important to recognise that individual consultation does not provide much more than one person's opinion, therefore it is unlikely to provide an informed response to policy debates or strategic decisions.

It is not uncommon for an individual disabled person to be invited to give their thoughts on a particular issue and for this to be seen as adequately representing the whole user perspective (Lindow V & Morris J). Although such an approach may ascertain individual experience and ideas, it does not provide the broader user-perspective that is required to make decisions.

Individual consultation is merely one form of user involvement, but it is often perceived as the only approach. This creates particular difficulties, when decisions are made on the basis of one person's experience. In addition, individual users who have not received adequate training and support will often seize the opportunity to discuss their personal circumstances and try to get their individual needs met (d'Aboville 1995). This may be appropriate in terms of ascertaining a particular person's experience if that is what one is specifically using individual consultation techniques for, but individual consultation should be recognised as only one type of user involvement which serves a particular function; it will not provide a broader picture.

Lindow and Morris in their synthesis of user involvement (1995) highlight a number of barriers to research on the involvement of individual disabled people in decisions, which affect their lives. These mainly focus on whether users are in a position to exercise choice and control over their own lives. Factors such as, i) concentrating on impairment rather than disabling barriers, (like professional

attitudes and assumptions), ii) lack of appropriate communication skills, and iii) the way services are organised and delivered, will prevent disabled people participating at an individual level.

Training, advocacy, support networks and other strategies to empower individual disabled people are essential if individual consultation is to work effectively (Lindow V & Morris J, 1995). At the moment most disabled people are not in a position to be able to assert their views and opinions because they have a history of other people making decisions about their lives, and they have rarely been given a proper opportunity to engage in a dialogue about what they want and how this can be achieved. This requires a major change in the role of many 'professionals' so that instead of becoming the decision makers and people in control they become a source of advice and assistance. Richard Wood, Director of the British Council of Disabled People, argues that by the year 2000, 'professionals' should take on a role similar to that of bank managers so that disabled people go to them to seek advice, learn about all the options available to them and then make decisions about the best course of action, rather than professionals taking a more dominating role (Wood, 1991).

### ***Group Consultation***

Parallels may be drawn between group consultation and community development techniques. With group consultation, advice and opinions are being sought on a collective basis.

Therefore self-help groups and organisations representing particular interests are asked for their ideas and thought. Disabled people are able to come together, share experiences and discuss appropriate responses.

Group consultation can take many different forms, ranging from discussions, quality circles, to receiving formal written responses to documents and using other group work techniques. It can address strategic policy issues and provide a broader picture of the relevant issues, because the focus is not on the individual, but rather on the matter being consulted upon.

In many ways group consultations can be easier to organise as the agency responsible for the consultation only needs to make contact with key individuals or organisations, and they in turn (if appropriately resourced) will work with other disabled people to prepare a response or attend a meeting. This form of consultation is likely to elicit more informed discussion and can feed directly into policy discussions. For example, a user group may act as an adviser to Council committees by ensuring their representative is well briefed on issues of interest on the agenda.

Group consultation requires a commitment of time and practical resources, such as funding, transport, sign language interpreters etc. Without such support the consultation process is likely to be limited to organisations or groups with well-developed infrastructures, which is much more likely to be organisations of non-disabled people. The difficulty with a lot of group consultations at the moment is that they rely heavily on responses to large, inaccessible print documents, such as architect's designs, planning applications and community care plans. Not only is it difficult for people to respond to unwieldy consultation documents, but also such work can consume a lot of the time and energy of small under-resourced organisations of disabled people.

Another major area of concern with group consultations is the fact that the views and ideas of disabled people are sought after proposals and plans have been made. Disabled people are placed in a position of being reactive, rather than proactive in the design and development of the political, economic, social and cultural context that they live in. Equally there is no guarantee that the views and ideas of disabled people will be taken on board as the agency embarking on the consultation exercise is free to accept or reject the comments received.

To ensure group consultations work effectively resources need to be put into organisations of disabled people (Lindow V & Morris J, 1995). Consultation work needs to be embarked upon early on, so that disabled people's organisation have time to consider an appropriate response and have their views at least acknowledged, if they can not be taken into account. Also training and the use of different consultation techniques should be encouraged if organisations are to be able to respond in a meaningful way (d'Aboville 1995).

Both individual and group consultation raise issues of accountability and representativeness. It is important to recognise that the two fulfill very different functions and offer differing degrees of representation. The disabled person who represents a group or organisation is there not to present their own experience, but to put forward the views and opinions of their organisation to whom they are accountable. In contrast, with individual consultation there is no line of accountability and the only interests represented are those of the person concerned.

To take the process of user involvement a stage further, one needs to consider the opportunities and limitations of joint working.

### **Joint working**

The notion of joint working now has a broad application, particularly since the introduction of community care planning and in the context of the education reforms where parents are considered to be 'partners' in the education of their child.

Community care legislation has been built on the philosophy of collaborative working, and for the first time it formally recognised the role of service users in shaping the design and delivery of services. Nevertheless, much of the focus has been on establishing joint planning mechanisms and consulting disabled people, rather than actively involving disabled people in setting the agenda and determining the delivery of services. Catherine Bewley and Caroline Glendinning found in their research on disabled people's involvement in community care planning that there was *“A little evidence of consultation with disabled people before the first version of a plan is drafted. This means that social services departments retain control of the overall content of the plan; disabled people are usually only invited to comment once a draft has been written. Disabled people therefore often find it hard to get onto the planning agenda issues which they consider to be essential for independent living...”* (1994:2).

Numerous agencies have set up forums to encourage joint working on issues of concern. For example, in some local authorities there are Joint Consultative Committees to address issues such as, health and social services, or police liaison. Such forums are usually made up of elected Council members, officers, representatives from appropriate agencies and a few advisers from community groups, like organisations of disabled people (d'Aboville 1995).

There is no blueprint for successful joint working; each organisation or agency sets up mechanisms appropriate to its needs. However the key factor which distinguishes joint working from other forms of user involvement, is that both disabled people and the agencies involved work together to plan and deliver services (d'Aboville 1995).

Joint working does not have to be in the form of meetings, it could mean disabled people and agencies have seminars, workshops or training together. Alternatively key individuals may be given tasks to undertake and then required to bring the different dimensions together. Also joint working might mean carrying out work such as recruitment, running a service or conducting an evaluation exercise together.

Potentially joint working can encompass any activity, if there is a will to share power and encourage participation. In reality joint working is often prevented by barriers, such as inaccessibility, lack of resources for disabled people to participate,

a reluctance to share decision making processes with disabled people, and a tendency to only involve disabled people in certain types of activities.

Joint working often gets confused with consultation, but the two are not synonymous. Joint working gives disabled people a more active participatory role, whereas consultation focuses on eliciting comments and views. Joint working can be put into practice throughout the design, delivery and monitoring of services. Indeed *Living Options Partnership* found that although there was a lot of diversity in the way joint working operated, and in some areas progress was patchy, there was evidence that disabled people were working jointly with service agencies to not only plan, but also implement and evaluate services (d'Aboville 1995).

Who has control over the decision making process and delivery of services are key issues when service agencies and disabled people are working together.

Some service agencies have taken steps to offer disabled people more participation by actually delegating control to service users.

### **Delegated Control**

Delegated control is where disabled people (or their organisations) take on responsibility for doing certain work. Organisations with statutory (or other) obligation to provide services can delegate the work to disabled people. This means that disabled people have control over how the service is designed and delivered, subject to the specification or contract agreed.

Delegated control lies at the top of the spectrum of user involvement because it offers disabled people the greatest degree of involvement. Indeed the development of delegated control has been substantially enhanced by the growth in disabled people's organisations, and the growing demand for user-led services.

The limited involvement of disabled people in the planning of statutory services has - in one sense - had some positive outcomes. The fact that disabled people have often been unable to directly influence the development of services run, or commissioned by, statutory authorities has traditionally given an added impetus for organisations of disabled people to develop their own alternative service models.

In the areas of personal social services and housing, for example, disabled people have developed personal assistance schemes and other independent living options, which are seen to be more appropriate to their needs than institutional forms of provision. Groups of people with learning difficulties - most notably *People First* - have also developed self advocacy groups which, amongst other activities, provide

a vehicle for individuals and groups to represent their views about local services and how they should meet their needs.

While these user-led services have continued to flourish amongst disabled people's own organisations, some have also been adopted by statutory agencies. Perhaps the clearest example of this has been the increasing numbers of local social services departments operating payment schemes which enable disabled people to arrange their own support packages instead of using public community care services.

There are also similarities with planning and the built environment. The fact that statutory planning authorities have often been seen as responsible for designing and developing accessible environments has prompted the development of local access groups run by disabled people themselves. One of the main activities which such groups have engaged in has been to monitor access barriers (e.g. by carrying out local access surveys) and producing access guides to assist disabled people with trying to negotiate these barriers. As with the development of alternative independent living schemes, such access groups are now seen as useful resources by local planning authorities. Consequently in some areas at least, access groups have provided a vehicle through which disabled people can become more closely involved in, and influence the development of, local planning.

For delegated control to work organisations need to be prepared to hand over power to disabled people. This can be extremely difficult when the culture and history of organisations places disabled people in the role of being passive recipients. Although a considerable shift has taken place in some organisations to facilitate delegated control, and user-controlled services are being encouraged through the contracting process, progress is likely to be limited unless disabled people are actively involved in making decisions about which areas of work they take on, and are properly resourced to do so.

### **Barriers to disabled people's involvement**

Whatever stage of the spectrum of user involvement is being looked at, there are a number of barriers to disabled people's involvement that have to be addressed. These include disabling attitudes, access barriers, resourcing issues and questions about representativeness. It is worth discussing each individually.

#### Disabling attitudes

Deeply held prejudice against disabled people often means that a major barrier that has to be confronted is that of disabled people being perceived as 'pathetic, tragic victims' or stereotyped as some form of 'hero'. Thus disabled people are not regarded as a part of mainstream society, but rather as a group of people who have to be 'protected', 'admired' or 'cared for' by society. This places disabled people in a passive role and fails to recognise that disabled people are not only experts in determining their own needs, but indeed they need to be able to participate as equal members of society (Barnes, 1991).

Disabling attitudes not only effect the way people respond to disabled people, but they also firmly place disabled people outside the realm of participating in a democratic society. Judgements are made about who can, and who cannot participate. Consequently certain groups of disabled people, such as people with communication impairments, people with learning difficulties and mental health survivors, are often considered unable to participate and therefore further excluded from any form of user involvement (Lindow V & Morris J).

A medical model of disability (Oliver 1990) serves to segregate disabled people further by separating them into certain categories, like visually impaired people, Deaf people and people with learning difficulties. This not only compounds the isolation disabled people may face as a collective group, but also it serves to act as a divide and rule strategy.

### Access Barriers

For disabled people to be able to participate in the political, social, economic and cultural environment that they live in, there are a number of practical obstacles that have to be overcome. For example, a blind person cannot vote in a local or national election unless the voting papers are made available in an accessible format. It is not sufficient to suggest that a Blind person can rely on someone else to help them vote, because this would mean impinging on their right to cast a vote in private.

Usually when people refer to access barriers, images of steps and wheelchair access spring to mind. Whilst physical access for people with mobility impairments is important, it is too easy to forget the needs of other disabled people. For example, it is meaningless inviting a person with learning difficulties to a meeting, or asking them to participate in staff recruitment unless there is someone available to support the person with learning difficulties and effort is made to avoid jargon and excessive paperwork.

Access barriers encompass a broad range of obstacles, ranging from physical barriers, to the amount of time allowed for responding to documents, not using

complicated language or enabling disabled people to take part in training or any other initiatives.

### Resourcing Issues

Whatever form of user involvement is being considered, practical and financial resources are required. Disabled people are offering their time, experience, skills and knowledge; therefore this should be acknowledged and resourced in an appropriate way.

One of the problems with community involvement initiatives that applies equally to user involvement, is the fact that individuals are expected to give up their time, energy and expertise for nothing. At the very best people may have their expenses reimbursed, or the organisation they represent may receive some form of grant to pay for user involvement, but very little funding will go directly to the individuals concerned. The argument for not paying disabled people directly is that it will effect entitlement to social security benefits, therefore it is not a viable option. Nevertheless, for disabled people to be able to participate as equal members of society resources need to be provided to encourage participation.

Planning and delivery of services can take up an awful lot of time and resources, particularly if it is a small organisation of disabled people with competing demands. Many organisations of disabled people are caught in a cleft stick. On the one hand they want to participate in the decision-making processes and take on as much control as possible, whilst on the other hand there is pressure on them to retain an independent campaigning role, and not become swamped by a service development agenda. Most organisations of disabled people have to try to achieve a careful balance between participatory initiatives and retaining their independence. This can be particularly difficult when an organisation is tied up with statutory agencies funding arrangements.

Resources need to be provided to cover practical matters such as transport, sign language interpreters, refreshments and so on. Also disabled people and their organisations should be reimbursed for sharing their skills, experience and expertise (Begum & Fletcher 1995, Lindow & Morris 1995).

### Representativeness

A persistent charge levelled against disabled people involved in user involvement initiatives is that they are not 'representative' of all users (Beresford and Campbell,

1994). It is worth exploring in more detail the issue of representation.

Traditionally there has been a tendency to ask organisations with an interest in disability issues to represent the voice of disabled people, rather than talking to disabled people directly. Although over the last decade there has been a substantial shift towards recognising that disabled people are experts in their own lives, there is still some tension between talking to non-disabled people, and involving disabled people directly. It is not uncommon for statutory agencies to talk to 'informal carers' or other non-disabled people about the 'needs' of disabled people rather than directly involve disabled people. Therefore although the debate about 'representativeness' usually focuses on the individual user or organisation of disabled people, it is important to recognise that it is a much wider issue about who can participate on behalf of disabled people.

Disabled people argue that the only groups that can represent their interests are those that have a majority of disabled people on their management committee and within their membership. Therefore organisations which purport to represent the interests of disabled people, but do not have a majority of disabled people at all levels in the organisation cannot represent the interests of disabled people.

Organisations of disabled people are elected by their membership, and all major decisions have to be agreed by their management committees and/or the directors of the organisations. There are clear lines of accountability and democratic processes are in place to ensure the organisation remains representative of its membership or users.

The other side of the coin in terms of the debate on 'representativeness' is whether organisations of disabled people only represent white, middle class, articulate disabled people (primarily men), and therefore cannot represent the interests of all disabled people (Beresford and Campbell 1994). Inevitably disabled people as a group encompass prejudicial ideas and beliefs like any other group. To some extent they may reflect this in their organisations. However, it is debatable whether disabled people's organisations can be expected to be more representative of their constituency, than larger scale public sector organisations.

Acknowledging concerns about racism, sexism, heterosexism, ageism and so on, many organisations of disabled people have taken action to ensure that black disabled people, disabled women, disabled lesbian and gay men, and other marginalised groups such as people with learning difficulties and Deaf people are included in their work.

Also groups of marginalised disabled people have established their own organisations to represent their own interests and work with other organisations of disabled people.

In view of the fact a lot of community development work was discredited because of concerns about élitism and issues about representativeness, it is important to find ways of recognising that specific work may need to be targeted at marginalised groups. Also, it may well be the case that more white, middle class disabled people have the time, energy and resources to commit to user involvement and disabled people's organisations, but this does not mean they cannot represent the interests of all disabled people. Public and private sector organisations need to be wary of applying standards for group consultation that they cannot comply with themselves.

Beresford and Campbell (1994) warn that the debate about representativeness is an old ghost which has been used as a defence strategy by those who feel threatened by the more participatory model of working. They explain that, *Issues around 'representativeness' are not new and they are certainly not confined to welfare services or their recipients. The same concerns and criticisms were raised by existing powerholders about the tenants, childcare, planning, neighbourhood and other grassroots organisations and movements which first blossomed in the community politics of the 1960s and 1970s. Other liberation movements... have all routinely come in for the same kind of criticisms. We can expect them to emerge whenever people and groups who have been disempowered struggle to empower themselves* (1994:315)

### **Lessons learnt from user involvement**

Across the country there are a number of different projects working on promoting the involvement of disabled people in the planning and delivery of services. However, a lot of the activity has focused on health and social services, but there are lessons to be learnt for other areas of work, therefore it is worth briefly summarising some of the key issues to emerge from projects like Living Options Partnership, Margin to Mainstream and the National User Involvement Project (d'Aboville, 1995; Goss and Miller, 1995; Lindow & Morris 1995).

- X Disabled people are being involved in the purchasing and delivery of services, and some innovative developments are emerging.

For example, in Riverside the Health Commissioner involved disabled people in the tendering process when awarding a contract for the wheelchair service. Greenwich and Bexley Health Commissioning Agency

paid a consultant to do outreach work with disabled people and draw up service specifications for key community health services.

- X User involvement is leading to the creation of innovative, new user-controlled services, which are providing good value for money. A lot of the user-controlled services are in the context of independent living schemes, however some organisations are providing day (and other) services in response to a particular demand from users. Asian People with Disabilities Alliance has established its own day service and provides an information and advice service for Asian disabled people. The organisation was instrumental in setting up *Apna Ghar*, a housing project for Asian disabled people.
- X User involvement has tended to concentrate on the planning of services. Although there are some innovative developments where disabled people are managing and/or evaluating services, these tend to be rather limited. A lot of the user involvement work has concentrated on information provision and consultation for community care plans (Bewley and Glendinning, 1994), but even at the early stages of the user involvement spectrum there is a lot of confusion about the purpose of user involvement, and disparity in terms of how it is being put into practice.
- X Community involvement techniques need to be used to reach a wide range of disabled people. Outreach work and facilitating meetings of disabled people is extremely important if disabled people are to be empowered to participate in the social, political, and economic life of the community.
- X There is a spectrum of user involvement depending on the type of activity and level of power disabled people have in determining the outcome. Each stage of the spectrum serves a particular purpose and has a valuable role to play, but agencies need to be clear about why they are using a certain type of user involvement and what they are aiming to achieve.
- X There are a number of barriers, like disabling attitudes and resourcing, that need to be overcome if disabled people are to participate effectively.

### **Measuring the level and effectiveness of disabled people's involvement.**

The participation of disabled people in the planning and delivery of services is a

means to an end, rather than an end in itself. It is extremely important to measure both, the level and effectiveness of disabled people's involvement.

1. In measuring how effective information is as part of the spectrum of user involvement it is necessary to look at factors such as:

- X whether information is in accessible formats;
- X how information is disseminated and how easy it is to use;
- X whether the information provided is distributed with sufficient timescales for people to act upon it; and
- X how can disabled people use the information provided?

2. To measure the extent to which disabled people are involved through individual consultation it may be useful to look at factors such as:

- X how easy it is to express one's opinions and ideas;
- X are disabled people included in consumer satisfaction surveys;
- X have disabled people had access to training and support such as advocates, self help groups etc; and
- X how easy is to make a complaint or disagree with people

3. To gauge the extent to which group consultation encourages the participation of disabled people in the planning and delivery of services, it is useful to look at factors such as:

- X are organisations of disabled people being consulted with;
- X what resources are put in to enable disabled people's organisations to participate;
- X at what stage of any development is consultation work undertaken;
- X is there any choice in the consultation method to be used;
- X how are the views of disabled people to be taken into account;
- X how much time is allowed for consultation work; and
- X does the consultation work make any difference to the final output?

4. To measure the effectiveness of joint working as a mechanism for enabling disabled people to participate in society, it is useful to look at factors such as:

- X at what stage are disabled people getting involved;
- X what types of activities is joint working used for;
- X who sets the agenda or determines the format of joint working;
- X are disabled people (or their organisations) paid for their expertise; and

X what outcomes have been achieved through joint working.

5. To measure the effectiveness of delegated control as a means of involving disabled people, the following factors may be considered:

- X what services do disabled people's organisations provide;
- X do disabled people have control over the decision making processes;
- X are disabled people's organisation independent of the organisation delegating responsibility to provide services.

6. Possible measures for considering disabling attitudes as a barrier to participation include:

- X Is the social model of disability understood;
- X How is the social model of disability applied to the planning and delivery of services;
- X Are disabled people divided up into different types of impairment groups?

7. In measuring the extent to which disabled people are excluded from participating in society, it may be useful to look at factors, such as:

- X amount of time allowed for participation;
- X complexity of the language used;
- X availability of sign language interpreters, Braille, tape, large print, minicomms, support workers etc;
- X physical access to buildings; and
- X availability of transport etc.

8. To assess how resourcing facilitates the involvement of disabled people in the planning and delivery of services, it is useful to explore the following measures:

- X Are practical resources (such as transport, support workers and accessible venues) provided to facilitate participation;
- X Are disabled people paid for their involvement in activities; and
- X Do disabled people have their expenses reimbursed;
- X Are organisations of disabled people funded for their involvement?

9. To determine the extent to which agencies are consulting in a representative way, it might be useful to look at factors such as:

- X Do agencies understand the difference between organisations of disabled people, and organisations for disabled people;
- X Is there clear guidelines on the distinction between working with 'informal carers' and working with disabled people;
- X Are representatives invited from democratically elected organisations; and
- X Are representatives selected on an individual basis or elected from representative organisations.

## **Discussion**

One of the most difficult issues around disabled people's involvement is that there is very little in the way of concrete evidence of the extent to which disabled people are involved. More importantly, there is no assessment of the degree to which such involvement makes any material difference to the kinds of services and policies developed.

One of the aims of the *Measuring Disablement* project is to develop appropriate methods for assessing both the process and outcomes of user involvement which can be used by local authorities and disability organisations to test how far they have come in promoting genuine participation of disabled people.

### **i) Measuring outcomes**

In developing these methods it is perhaps easiest to start with defining the kind of outcomes which it would be appropriate and desirable to test for. At the most general level, the key outcome of involvement is obviously whether or not disabled people are able to shape the services and policies which affect their lives. However, in most cases, it is unlikely that such an outcome can be defined in absolute terms for two main reasons.

First, the nature of local involvement often means that practical outcomes only occur over a period of time. Therefore, it will often be very difficult to state conclusively whether or not a particular result has been achieved. For example, a local authority may - after a process of consultation and negotiation - make a formal commitment to a particular access initiative or to the development of a local resource centre or CIL. Putting this into practice however may take a period of years and, at any particular point in time, it may only be possible to test how much progress has been made rather than whether or not the intended outcome has actually been achieved conclusively.

Second, most planning processes take place within a context of competing claims

for resources. There is always a possibility, therefore, that the outcomes which are desirable for one group have to be weighed against the outcomes wanted by another. Similarly, commitments made at a local level are often constrained by the policy or legislative framework set by central government. Consequently, the kinds of practical outcomes which emerge from local negotiations will often be characterised by compromises by all or some of the parties involved.

A good illustration of this has been the campaign (which has been promoted both nationally and locally) for direct payments for personal assistance. Until very recently, local authorities have been prevented from making direct payments by the legislation enforced by central government. Despite this, some have gone much further than others in seeking ways around the existing legislation while one or two have - at least until they were warned to stop by the Department of Health - continued to make direct payments even though this was effectively against the law. So, if a local organisation of disabled people had been negotiating for the introduction of a payments scheme but had failed to get one, should this be defined as a failure of local planning or a result of government legislation? On the one hand, if some local organisations have been successful in influencing the development of a local payment scheme, this would suggest that this can be viewed as legitimate outcome of the planning process. On the other hand, local authorities who have declined to meet local demand for a payments scheme could legitimately argue that they were prevented from doing so. Consequently, they would presumably disagree with the development of a payments scheme being viewed as legitimate outcome for testing the effectiveness of disabled people's involvement.

It is clear, therefore, that we need to clarify what kinds of outcomes can be viewed as legitimate in the context of assessing the effectiveness of any participation in local planning.

Further, given that it is almost certain that we would be unable to arrive at definitions which could attract universal acceptance, it would probably be more fruitful to think in terms of a continuum of outcomes which could be applied to the assessment of particular involvement processes.

For example, one end of the continuum could, in theory at least, be defined by maximum influence at the individual level (ie. any disabled person being able to have their views listened to and acted upon). The other extreme would obviously be defined by disabled people having no influence at all (i.e. their views not even being listened to, let alone acted on).

However, it would also be important to consider the different levels at which such a continuum should be applied. A community care assessment for example should quite properly be assessed in terms of whether or not an individual disabled person

is able to influence the outcome. A major town planning review on the other hand would be very difficult to evaluate in this way, not only because negotiations tend to be carried out a more collective level, but also because there would clearly be too many individual opinions to take into account when evaluating whether or not they have been acted on. In this kind of situation, therefore, any measurement of the degree of influence which disabled people have over the outcome of the involvement process would have to be made at a higher level of aggregation.

At a different level again, we should also be considering how it might be possible to develop measures which indicate the degree to which participation in local work contributes to the collective empowerment of disabled people.

Another issue which needs to be considered is the relative weight which should be placed on the objective and subjective dimensions of disabled peoples' influence on local involvement. Given that outcomes will often not be absolute, it may well be that the measurements also need to take account of the relative degree to which disabled people feel that they have been to influence the planning process. For example, this could be measured by - amongst other things - the extent to which people feel confident that a particular outcome will be achieved, either within >the foreseeable future, or by a given point in time.

Case studies in two local authorities will hopefully offer the opportunity to clarify some of these problems with defining outcomes and to test out some practical options for developing appropriate measurement techniques.

In this context, the most useful part of the case studies will probably be the surveys of local disabled people which will provide a vehicle for testing out questions designed to assess issues such as how much people know about local user involvement mechanisms; whether or not they would know how to make their views known if they wanted to; whether or not they are aware of/in contact with local representative organisations of disabled people who might express their views on their behalf; and, whether or not they feel they are able to have any influence on the development of local policies and services. At another level, the case studies may also offer the opportunity to look at specific initiatives (either recent or current) in terms of how they have been developed; who was involved; what practical mechanisms and resources were available to facilitate involvement of different groups of disabled people; and, the views of some of the parties involved. In Manchester, for example, it has been suggested that we could examine the planning and consultation which is currently going on around urban regeneration in the city, while in Leicester there may be similar opportunities to look at the involvement of disabled people in strategic planning on housing and social services in the run up to the formation of a unitary authority.

## **ii) Measuring the process of participation in local planning**

There is a growing literature on both local and national initiatives around user involvement. Although much of this literature is pitched in terms of general principles of good and bad practice, it should be possible to draw out some of the specific implications for evaluation. Probably the easiest way into this would be to start by listing all of the key activities and processes which, according to the literature, contribute to effective and participatory planning processes. This will then provide a framework which will help us to think about translating these into operational measures which can be tested by the research.

Some of these measures may be in the form of checklist questions (e.g. do social services planning groups routinely provide sign language interpreters at all of their meetings?). Others may be linked to trying to determine how much a local authority actually invests in facilitating participation (e.g. whether or not fees are paid to user representatives). Others may need to be pitched at a more general level (e.g. questions about whether or not local authorities seek feedback from disabled people about different planning processes and, if so, what form this takes?).

In addition, we also need to think about ways of measuring the actual level of involvement of local disabled people (e.g. in terms of the number of planning groups which involve representatives from local organisations of disabled people; numbers of public meetings and so on). However, it is important to remember that such measures will be of limited use unless they are combined with measures indicating the actual quality or effectiveness of such involvement. (For example, there is little point in knowing that a local authority held 50 public meetings on their community care plan unless we also know something about whether or not local disabled peoples' views were actually incorporated into the plans as a result).

We will also need discuss the development of appropriate measures with some of the disability organisations whom we are consulting with about the project. Derbyshire Coalition for example, have been working on a checklist for evaluating the level of participation in planning by disabled people and they are quite keen on us looking further at this issue together. They have also suggested that we could use their extensive network of user panels to test out some of the measures when we are ready. Wiltshire Users Network are also able to offer some views on the approaches they have taken and the obstacles they have had to try and overcome. All of this will obviously be a great help in trying to define and operationalise the key issues we need to take into account.

## **Conclusion**

This paper has outlined how user involvement has become part of the national policy agenda, particularly exploring the parallels between community involvement and user involvement. There has been a detailed discussion about the spectrum of user involvement, highlighting some of the factors that need to be borne in mind when measuring the extent of disabled people's involvement. After identifying some of the barriers to disabled people's involvement and summarising the key issues to emerge from work on user involvement, the paper goes on to discuss the possibilities for measuring the level and effectiveness of disabled people's involvement.

It is possible to conclude from the discussion in this paper , that user involvement is a key feature of social policy which can be regarded as analogous to community involvement initiatives.

There are many different ways of involving disabled people and the spectrum of user involvement is a useful way of understanding the purpose and results of initiatives which encourage participation. It is essential to measure the level and effectiveness of involving disabled people, however developing reliable measures requires considerable work. In the process of developing measures it is necessary to explore both, the process and outcomes of involving disabled people. This is rather difficult, as there are different perspectives and constraints to take account of. Nevertheless, there are some tangible measures, which can be derived from considering the spectrum of user involvement and exploring the aims and objectives of disabled people and service agencies. Further work needs to be undertaken to develop measures, which can serve as a benchmark for measuring the extent to which disabled people are being involved in the social, political and economic life of society.

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