Research Review on User Involvement in Promoting Change and Enhancing the Quality of Social 'Care' Services for Disabled People

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Contents

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Summary

The Social Care Institute for Excellence (SCIE) commissioned this Research Review to examine current knowledge and thinking on adult user involvement in the initiation, development and delivery of social 'care'[*] support services for disabled people. It specifically excluded studies of user involvement for disabled people labelled 'with learning difficulties', 'mental health systems users and survivors' and user involvement in social 'care' research, as these are the subjects of separate SCIE reports.

The Review had the following objectives:

1. Identify published and grey literature evidence on approaches, methods and outcomes of disabled people's involvement in social 'care' services at the local and national levels.

2. Consult with key local and national groups and organisations with a particular interest in service user/'carer' involvement.

3. Sort and map the collected materials with reference to three classifying headings: a) disabled peoples' involvement, policies and practices; b) context and outcomes; and c) barriers, both local and national.

4. Critically evaluate collected materials.

5. Identify gaps in the research to date and produce a list of policy and research implications.

The Review begins with a brief 'introduction' that provides a general background and includes details of the discussions on its form and content with representatives of national and local organisations controlled and run by disabled people.

Section 1 outlines the literature search strategies. Subject headings and searches varied as appropriate to the various databases reviewed and covered user/consumer: involvement, participation, representation, control; service delivery, independent, inclusive, integrated living and

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[*] As noted in Section 5, ii, of this Report, the words 'care' and 'carer' are regarded by the disabled people's movement as paternalistic and dependency creating when used with reference to disabled people. Social 'support' is currently considered the more appropriate phrase for disability related services. Adult disabled people require 'helpers', 'support workers' or 'personal assistants'.

direct payments. The literature search highlighted the shortfall in systematic and comprehensive studies evaluating the relationship between disabled user involvement in social 'care' services and specific quality effects and outcomes. Further information on the search strategy is contained Appendix 1.

Section 2 explores the main factors underpinning the growing demand for user involvement and key legislative responses. These include the changing economic and cultural context since the mid-twentieth century, the politicisation of disability by disabled people and their organisations, and the ensuing emphasis on self-help, user control, and independent living.

Section 3 focuses on the recent shift towards greater user involvement in statutory and voluntary organisations, both *of* and *for* disabled people, and its impact on policy outcomes. The discussion emphasises three types of involvement: user control, participation and partnerships, and consultation. Examples of good practice are provided. While considerable progress has been made in the development of user led services, working partnerships between user-led and non user-led agencies and user consultation, there is still some considerable way to go.

➢ Progress in the development of user led provision and support is limited and geographically uneven,

➢ There is an under-representation of some sections of the disabled population in user led initiatives,

➢ The association between user and non user-led organisations sometimes inhibits user involvement and provision.

➢ Consultation procedures often have little relevance to policy changes and outcomes.

Section 4 foregrounds the principal barriers to user involvement and user-led social 'care' services. The studies reviewed indicate that despite the growing emphasis on user participation in policy and provision, meaningful user involvement in health and social support services remains relatively small in comparison to the disabled population as a whole. This is attributed to:

➢ Financial and organisational considerations that prioritise a particular set of economic and political constraints over formal commitments to meaningful user involvement and policy change.

➢ Core funding is a major and perennial problem for all user-led initiatives and provision.

➢ The future development of user-led services is threatened by funding agencies' formal and bureaucratic practices that implicitly if not explicitly favour established non user led agencies.

➢ The imposition of strict eligibility and assessment criteria for access to social support services undermines the notion of meaningful user participation and choice.

➢ Whilst there has been some attempts to address the relevant issues, all too often professional policies and practices continue to generate a range of initiatives in which user involvement represents little more than tokenism and an exercise in user education.

➢ The psycho-emotional consequences of coming to terms with impairment, whether congenital or acquired, in a society geared almost exclusively to non disabled lifestyles acts as a personal barrier to user involvement.

➢ Despite the publication of several good practice guides there is evidence of a general lack of awareness amongst managers and practitioners of the various support mechanism needed to facilitate disabled users involvement in social support service development and delivery.

The Review concludes, in Section 5, that user-led organisations and user consultation operate within an ever-changing economic and political landscape that makes for considerable difficulties in providing continuity in policy and planning. Recommendations are offered for areas that will benefit from practice guidance and research that is user-led.

Introduction

Over recent years, an increasingly central theme in government policy has been a commitment to public and user involvement in shaping public services and local policies and practices. In the health and social 'care' fields, there is now a statutory duty on local social services to provide for user involvement and scrutiny. The focus on adult disabled peoples' involvement is explained by a variety of economic, social and political factors, including the politicisation of disability by disabled people and their organisations. They have emphasised the significance of self-help groups and user-led organisations at both the local and national levels in developing initiatives to enhance the quality of services for disabled people and their families.

The Report is divided into five sections. The first outlines the literature search strategy. The second deals with the growing demand for disabled people's involvement in social 'care' services, policies, and practices. The third section centres on the context in which user involvement takes place and its main types. The fourth section identifies some of the economic, political and social barriers to user involvement. The Review concludes with selected policy and research recommendations.

In compiling this review, its form and content have been discussed with disabled representatives of the following user controlled organisations: the British Council of Disabled People, the National Centre for Independent Living, Disability Wales, Lothian Centre for Integrated Living, Derbyshire Coalition for Inclusive Living. This took the form of telephone interviews with key informants, selected by each organisation, one week before the initial submission date (30th June) for this report. A penultimate draft had been forwarded to these organisations along with a request for participation two weeks earlier. Following these discussions appropriate amendments were made to this Research Review before its submission to SCIE.

1. The Literature Search

The first stage entailed a scoping of the literature on disabled user involvement and, following initial inspection, the generation of search questions (Godfrey *et al*. 2000; Long *et al*. 2002). The inclusion criteria comprised studies dealing with (current and past) disabled user involvement in promoting change and enhancing the quality of (non-private) social 'care' services in the UK (see Appendix 1). A timeframe

from 1993 to 2002 was adopted. The SCIE brief specifically excluded consideration of people labelled with learning difficulties and mental health systems users and survivors, as well as user involvement in social 'care' research, as these are the subjects of separate SCIE reports.

Searches were conducted on a range of databases: ASSIA, CINAHL, Cochrane Library, MedLine, and Web of Science. Unpublished or 'grey' literature were also identified from specialist databases such as Caredata, Centre for Evidence Based Social Services (CEBSS), LARIA (Local Authority Research in Action), and System for Information on Grey Literature in Europe (SIGLE). Subject headings and searches varied as appropriate for each data base but concentrated on: user/ consumer involvement/ participation/ representation/ control/ led, social (care) services, service delivery/ service change/ service quality, independent /integrated / inclusive living, and direct payments. Hand searching of selected social policy journals and books published between 2000 and 2002 and located in the University of Leeds library was also undertaken. Additionally, materials were collected from organisations of disabled people, notably newsletters and reports, plus over a hundred websites (see Appendix 1 for further details).

The literature search produced a striking absence of studies attempting a systematic research-based evaluation of the relationship between disabled user involvement in social 'care' services and specific 'quality' effects and outcomes. This conclusion echoes earlier reviews of social 'care' (Baulcombe *et al*. 2001), and of user involvement in health services (Crawford *et al*. 2002). Instead of studies of the effectiveness of user involvement perhaps utilising quasi-experimental research designs, the favoured approach has been to gather survey or qualitative data on the perceived impact of user involvement. This is typically based on ratings by service users, managers and professional providers of their satisfaction with the process and/or outcomes. There is also a wider literature exploring various forms or categories of user involvement. However, studies have been slow to focus on services for disabled people, and specifically those disabled users covered in this report.

2. Involving Disabled People

i. The demand for change

The growing demand by disabled people and their organisations for much greater involvement in social 'care' services is rooted in the economic and political upheavals of the 1960s. Most notably, the welfare state failed to counter the exclusion of people with accredited impairments from the mainstream of community life (Barnes 1991; Campbell and Oliver 1996). There was also increasing criticism of the paternalistic, dependency creating services controlled and run by non-disabled professionals (Davis 1993; Oliver 1996). This led to the emergence of civil rights campaigns by other economically and socially disadvantaged groups that in turn stimulated disabled people to set up organisations that they controlled (Evans 1993; Oliver 1996).

The focus on user-led initiatives was associated with a redefinition of disability as a socio-political issue (UPIAS 1976), underpinned by a social model of disability (Hasler 1993). Its emphasis on the economic, environmental and cultural barriers confronting people with accredited impairments won gradual recognition from policy makers and professionals around the world (Orshot and Hivenden 2000; WHO 2001). Social model advocates acknowledge that appropriate medical interventions are necessary and often beneficial, but maintain that these must not submerge the need for radical social and environmental changes to facilitate disabled people's inclusion in everyday community life (GLAD 2000).

The political campaigns by disabled people and their organisations concentrated on securing service support for 'independent living'. While its meaning is contested (Higgins 2002), most accounts underline the significance of support for user-led services for everyday living in the community living (Barnes 1993; Bracking 1993; Evans 1993; Morris 1993, 1994; Zarb and Nadash 1994; Barnes, M. *et. al*. 1998). Independent living is distinguished from other ways of meeting disabled people's support needs in two key respects:

- choice – over where to live, how to live and who provides assistance; and
- control – over who assists, how, when, and what they do (Hasler, Campbell and Zarb 1999: 2).

ii. Legislation

The combination of a growing disabled people's movement, an escalating welfare budget, and a swing to the right in British politics, precipitated

moves towards the involvement of disabled service users in the planning and delivery of services. An early example was the Disabled Persons (Services, Consultation and Representation) Act, 1986, although it was scarcely enforced (Bewley and Glendinning 1994).

On a different path, the Government introduced the Independent Living Fund (ILF) in 1987. Half the trustees were nominees of the Department of Health and Social Security (DHSS), with the remainder from a user led organisation: the Disablement Incomes Group (DIG). The ILF was established for a maximum of five years with a budget of £5 Million, and had the power to make 'direct payments' to a small number of disabled people to help organise their own support system by employing personal assistants (PAs) (Kestenbaum 1993, 1996).

However, official thinking was mostly dominated by a perception of user involvement rooted in consumer sovereignty and choice, and the potential of market competition to enhance social 'care' services. This underpinned the National Health Service and Community Care Act 1990. Indeed, its emphasis on the importance of informing, consulting and involving people who use health and social services (DoH 1990, 1991) still pervades social 'care' legislation and policies (Cook 2002). As an illustration, the 1994 Framework for Local Community Care Charters in England stressed the involvement of users and 'carers' in the assessment of needs, inspection of care homes and other services, and future service planning (DSS 1994). The emergence of disabled service users as consumers was further evident in the Community Care (Direct Payments) Act 1996. This enabled local authorities to allocate direct payments to groups of disabled users to purchase and control their own support services/personal assistance (Glasby and Littlechild 2002).

The 'Best Value' process has been similarly designed to enhance efficiency and effectiveness in local services by highlighting local community and user involvement. *Modernising Social Services* (DoH 1998) emphasised local user satisfaction surveys, with subsequent calls by the Association of Directors of Social Services for a joint approach to user feedback across health and social 'care' services (Hudson 1999: 19). Further recent Government initiatives have included the establishment of a General Social Care Council (GSCC), and the Social Care Institute for Excellence (SCIE). The Care Standards Act (2000) established a new regulatory body, the National Care Standards Commission (NCSC) with responsibilities that include social 'care' services, and taking over the inspection and regulation of services from local authority and health inspection units (NCSC 2003). Additionally, the Health and Social Care

Act 2001 and NHS Reform and Health Care Professionals Act 2002 outlined principles for a new user involvement structure in service arrangements. Another potential influence is the incorporation into UK law of the European Commission on Human Rights and Fundamental Freedoms following the Human Rights Act 1998.

The recent move to devolution has created the potential for more variation across the UK. User-led groups operate in contrasting national as well as local political and policy environments, although there remain many similarities, even if slightly different implementation patterns. These are evident in the 'Joint Review' reports on progress towards enhancing the efficiency and effectiveness of local social services in England and Wales. These display common ground in collecting evidence directly from users and 'carers'. They also stress moving beyond the 'old solutions' of formal consultation and nominal representation on planning groups. The 'new solutions' identified centre on encouraging closer relations with users and carers, direct payments, and involvement in Best Value and commissioning decisions (Audit Commission 2001). Despite the presumption about 'what works' there is little attempt to demonstrate in more depth what worked, how, with whom and why? (Cook 2002).

Proponents (particularly managers and politicians) of involving people as consumers argue that it 'drives up standards' and constrains professional power. However, the difficulties of exercising consumer rights in the context of health and social 'care' have been widely documented (Wistow and Barnes 1993). A clear contrast is drawn with user involvement that is framed in terms of citizenship rights. From this perspective, it becomes an exercise in engaging with hitherto excluded groups and generally renewing the democratic accountability of social and political institutions and processes.

Even then some critics argue that user involvement is too easily exploited as a 'technology of legitimation'. Thus, it sustains management and government authority by giving the appearance of democratising public services without allowing policy shifts in 'undesirable' directions (Harrison and Mort 1998). Indeed, managers and professionals are both prone to 'play the user card' in trying to win a policy dispute.

3. Patterns of Involvement and Outcomes

Historically, Britain has been more of a 'passive' rather than a 'participatory' democracy (Beresford and Campbell 1994), and user-led

initiatives present an exceptional counter trend. Yet overall, the moves towards greater involvement of service users have been slow to recognise the specific support needs of disabled people, or how far these vary within the disabled population. As an illustration, studies have consistently identified concerns about the lack of service support for disabled people from minority ethnic backgrounds (Begum, Hill and Stevens 1994; Hasler, Campbell and Zarb 1999; Bignall and Butt 2000; Hussain, Atkin and Ahmad, 2002; Shah and Priestley 2001). There is also a shortfall in support for disabled people living in rural areas (Craig and Manthorpe 2000).

Since the 1960s, there has been a series of reforms formally recognising and encouraging the role of services users in service planning and delivery (Craig and Manthorpe 1999; Drake 1999; Goodinge 2000). The backing for user involvement in government legislation and local authority statutory services has been complemented by the positions adopted by a wide and differential range of major national and local organisations concerned with disability. This is reinforced by the diverse support that now exists for a social model approach and the philosophy of independent living. The organisations span the Leonard Cheshire Foundation (Carmichael, Brown, and Docherty 2000), NHS Trusts such as Liverpool NHS Primary Care Trust (Clarke 2002) and local authority social service departments, for example, Leeds Social Services Department (LSSD 2001, 2003). The Disability Rights Commission (DRC 2002) also espouses similar goals.

Moreover, several traditional organisations *for* disabled people controlled and run by non-disabled people have evolved into organisations *of* disabled people, by changing their constitution to ensure that disabled people are in the majority on their controlling bodies. For example, at their recent annual general meeting Disability Wales/ Anabledd Cymru agreed, 'with immediate effect', that their executive committee and Chief Executive will comprise only disabled people. Moreover, from 2007, full membership and voting rights will be open only 'to those organisation or groups where disabled people have a constitutional majority in their voting membership' (Disability Wales 2003: unpaged).

i. Types of involvement

The potential for user involvement ranges across many different aspects of service planning and delivery. These include prioritising needs and resources, planning and purchasing services, developing assessments, packages of care, monitoring, reviewing and evaluating services. The

assumption is that being involved in negotiating decisions will be followed by meaningful co-operation in their implementation.

There is now an established tradition of representing user involvement in terms of a 'ladder' of participation (Arnstein 1969). These range from the generally low levels of participation characteristic of traditional professionally-led services, to the more recent user/provider partnership and user-led approaches. For the purposes of this review disabled people's involvement in services provision will be discussed under the following headings: user control, user participation, and consultation.

a) User control

Since the 1960s there has been a steady growth of service provider organisations controlled and run by disabled people at national, regional and local levels. At the national level, examples range from groups such as the Spinal Injuries Association (SIA) to the National Centre for Independent Living (NCIL). NCIL was set up in 1997 by the British Council of Disabled People's (BCODP) Independent Living Committee, and provides a range of services to support the promotion of independent living and personal assistance use in the UK. BCODP is the national umbrella for organisations controlled and run by disabled people, with a membership of over 130 groups (BCODP 2003).

In Scotland, examples include the Scottish Personal Assistance Employers Network (SPAEN) and Inclusion Scotland. The former is a Scottish user-led support service, and the latter is an umbrella organisation for organisations controlled and run by disabled people. Disability Wales is the national umbrella for disability organisations in Wales.

Recent research sponsored by BCODP and NCIL identified at least 85 user-controlled organisations that provided a range of support services for disabled people and their families across the UK (Barnes, Mercer, and Morgan 2000). Although varying in size and resources, user-led organisations are characterised by formal mechanisms to ensure: control by disabled people, high levels of accountability to members, employment policies that favour disabled paid and voluntary staff, and a commitment to the social model of disability and independent living. Nevertheless, user-led organisations are very unevenly distributed. The majority are located in south-east England and the midlands, while Scotland, south-west England, and Wales have the fewest (Barnes, Mercer and Morgan 2000).

Most of these organisations offer a range of services, although none offered all of the seven needs for independent living identified by the Derbyshire Coalition of Disabled People in 1985. These are information, counselling, housing, technical aids, personal assistance, transport, and access (Davis and Mullender 1993). Nevertheless, some user-led organisations provide a very wide range of services including education and employment advice and support, and Disability Equality Training whilst others provide information and advice on services provided elsewhere (Barnes, Mercer and Morgan 2000).

Table 1: Services offered by user led organisations

Service	Currently offered	Hope to offer
Information	**82%**	**65%**
Peer support by disabled people	**67%**	**13%**
Disability/distress awareness/equality training	**58%**	**9%**
Personal assistance	**54%**	**8%**
Employment advice/training	**38%**	**12%**
Housing advice	**36%**	**15%**
Environmental access	**32%**	**13%**
Education advice/support	**30%**	**12%**
Transport	**22%**	**6%**
Counselling	**16%**	**20%**
Health/impairment related	**15%**	**9%**
Technical aids & assistance	**13%**	**6%**

Source: Barnes Mercer and Morgan (2000: 22).

There was overwhelming agreement that user-led organisations were far more responsive to disabled people's support needs both in terms of what was on offer and how it was delivered, with advocacy and peer support a major consideration (Barnes, Morgan and Mercer 2001).

Nevertheless, structural and cultural barriers contribute to an under-representation of some groups amongst disabled users. These include people from minority ethnic groups, lesbian and gays, and younger

disabled people (Barnes 1995; Barnes, M. *et al*. 1999; Barnes, Mercer and Morgan 2000; Morgan, Barnes and Mercer 2001; GLAD 2002).

However, user-led organisations strive to be inclusive and many have developed projects aimed specifically at particular sections of the disabled population. For example, Greater London Action on Disability (GLAD) has set up the 'Count Us In' project to provide sustainable support for Black and minority ethnic disability groups in London. The project provides advice and support on different aspects of running a voluntary organisation. In collaboration with other agencies such as Community Volunteer Services (CVS) this includes, fundraising, training, collaboration in conferences, networking, publicity, and consultation on issues relevant to disabled Londoners from Black and minority ethnic backgrounds (see: www.glad.org.uk/projects/).

Several user-controlled organisations provide support services for recipients of direct payments. These are widely accepted as a key aspect to independent living because they enhance user choice and control. In 2000, there were 3,612 people receiving direct payments in the UK (Jones 2000), and by September 2002, this had risen to 7,882 (DoH 2003). A wide range of research studies have reported that PA users prefer this type of support to other forms of social provision (Lakey 1994; Zarb and Nadash 1994; Kestenbaum 1993, 1996; Dawson 2000; Glendinning *et al*. 2000; Witcher *et al*. 2000; Barnes, Morgan and Mercer 2001; Evans and Carmichael 2002).

Again, the provision is uneven geographically with, for example, disproportionately more PA users in south-east England (Jones 2000; DoH 2003). Many local authorities have been extremely reluctant to introduce direct payments, while some within the disabled community have found it difficult to access payment schemes. These include older disabled people (Barnes 1997), those from minority ethnic groups (Begum 1993; Butt, Bignall and Stone 2000) and disabled lesbians and disabled gay men (Killin 1993). There are recurring obstacles that include a lack of appropriate information and awareness among professionals, and a lack of peer support (Hasler, Campbell and Zarb 1999; Pearson 2000; DCIL 2003; Glasby and Littlechild 2003).

Further examples of user-led services may be seen in the activities of Centres for Independent/Inclusive living. At the national level, NCIL provides information leaflets around key issues such as charging for community care services, the costs and benefits of independent living, personal assistance and direct payments. An illustration of local action is

provided by Southampton CIL's involvement in training consumers of services to audit local authority services from the perspective of users. This has increased understanding among social workers of the impact of good and bad packages on disabled people's lives (Batty 2001). Subsequently, Southampton City Council's Health and Social Care Directorate commissioned Southampton CIL's Disabled Person's Consultation Forum to consult with disabled people (including older disabled people and people with learning difficulties) on a whole range of issues. These include access, and consumer audits, designed to inform future commissioning plans and user consultations on social services support for independent living (see, for example, SCIL 2003).

In addition, one of the major achievements claimed for the National User Involvement project is that the perception of disabled people as passive service users had been shifted. As a result of its activities, there was much more appreciation of disabled people as experts in their own support needs, who should be consulted appropriately (Lindow 1999).

b) Participation and partnerships

Since the 1970s, organisations *of* and *for* disabled people have become an important feature of the service sector landscape. This is especially evident in the provision of information (Barnes 1995; Moore 1995). DIAL UK, for example, is a national disability information and advice service, although no longer user-led it was originally set up by disabled people (Davis and Mullender 1993). Currently, it supports over 140 outlets, many of which are directed by and run by disabled people.

Identifying user-defined outcomes is a lengthy undertaking and cannot easily be separated from 'process' issues. It also extends beyond the remit of social 'care' to services such as transport, housing, employment, income and benefits, discrimination (Turner, Brough and Williams-Findlay 2003). However, there are examples of innovative practice in consulting with disabled users about services, including its design and implementation. For example, a project group of disabled people was set up in one local authority to design and undertake a review of direct payments using the statutory Best Value framework (Evans and Carmichael 2002).

Furthermore, user-led organisations have developed partnership arrangements with other agencies. For example, data from the *Creating Independent Futures* (Barnes, Mercer and Morgan 2000) project indicates that more than half the organisations surveyed have formal links with, or

are members of, other local organisations. The majority has links with local organisations controlled and run by disabled people (75%) and with other voluntary organisations (62%). Around a third of groups have links with organisations *of* people with specific impairments (39%) and local groups for disabled people (31%) Smaller numbers have links with organisations *for* people with specific impairments (21%) and different impairments (15%) and 'carers' groups (15%). Thirty-nine per cent are formally attached to local authority social services departments and twenty-one per cent to a health authority. Additionally, almost three-quarters (74%) are formally attached to national organisations. Eighty-two per cent are attached to national organisations *of* disabled people, with less than a quarter linked to national organisations *for* disabled people (23%). Ten per cent of groups were associated with national organisations *of* and *for* disabled people with specific impairments

These associations are frequently mutually beneficial, although some disabled people express concerns that this sometimes inhibits appropriate user control (Barnes, Mercer and Morgan 2002). In response to growing concerns over the fragmentation of services and the ensuing problems for service users, more integrated local initiatives are being introduced. For example, Sandwell Metropolitan Borough Council set up a joint planning group comprising the local authority, NHS, the voluntary sector and users and 'carers'. One of its actions has been to establish a Disabled Living Centre 'committed to empowering disabled people' (DoH 1998: 39).

ii. User consultation

Nationally, agencies such as the NHS and the General Care Council have developed consumer consultation programmes. At the local authority level too, users have made an input to the development of services. One illustration is Manchester's 'Physical Disability Services' team, that set up the 'Physical Disability Service Reference Group' comprising disabled people, 'carers' and social services staff. It meets quarterly to discuss the 'planning, development, delivery and evaluation of the physical disability' service and produces a regular newsletter on relevant issues (North 2003). Additionally, sub-groups have contributed to the development of day 'care' facilities, accessible housing, and the expansion of direct payment schemes. As a result Manchester was one of the first authorities to offer direct payments to 'parent carers and young carers' (PDSRG 2002: unpaged).

Since 1997, Joint Service Reviews have provided wide-ranging 'official' documentation of the progress towards user involvement in service

development. The report for Wales (Audit Commission 2002b) reports from user surveys that the percentage rating services as good or excellent varies from 60-85% across Wales - similar to the English experience - and yet problems and dissatisfaction in specific aspects of social 'care' are also noted.

> Better councils are more actively involving users in shaping changes, setting standards and monitoring progress. Best Value has encouraged politicians, users, and partners to collaborate in new ways to achieve good quality at the best price (Audit Commission 2002a: 5).

The Joint Reviews Overview Report for England 2001/2 (Audit Commission 2002a) highlights Gloucestershire, Wirral and Shropshire as examples of good practice. This is highlighted in the ways they have enlisted, 'the support of users and carers in some very difficult changes, such as the introduction of new charging policies, the redesign of specific services, staff appointments and developing user-run services' (p. 40). In Shropshire, the local day centre was subjected to Best Value Review and as a result placed under the management of the Shropshire Disability Consortium on a three-year contract – an advocacy organisation that also now delivers services. It has also re-ordered its activities and priorities in line with disabled people's preferences, such as negotiating a new transport service for users. However, there has been no systematic evaluation of developments in Shropshire from a user perspective (Bott 2003).

Devolution in the UK is encouraging different pathways to achieving relatively similar social 'care' policy goals. In Wales, the Joint Review Team argues that new mechanisms are now in place to champion the cause of the user. The emphasis is on a culture of involvement and listening and acting on feedback. Recent reports detail areas where identified problems have been addressed. For example, Cardiff's poor record on providing mobility aids and adaptations, delays on occupational therapy assessments in Newport, and at Neath Port Talbot's disablement assessment service (Audit Commission 2002b: 18). In fact, the new Disability Action Centre was set up in Neath Port Talbot by the Shaw Trust with significant European Commission and Lottery/Community Fund funding to provide services for people with physical and sensory impairments, including direct payments and an independent living scheme. However, this is a non user-led organisation and this example, replicated in other parts of the UK, illustrates the increasing competition facing local user-led organisations.

Service providers in the voluntary sector have also begun to initiate polices for greater user involvement in policy development. The Leonard Cheshire Foundation in the South Western region, for example, has conducted extensive research to seek the 'views of potential service users, existing service users, family carers, and service purchasers' to assist the foundation with their regional planning process (Carmichael, Brown and Docherty 2000).

However, it is evident that much attention has been given by service providers over recent years to the *process* of user consultation but relatively less concern about *why* to consult or to *what end*. If the reason for consulting disabled people is not clearly thought through then the form of consultation becomes more important than the content or outcome. The establishment of mechanisms for consultation or involvement is not always translated into meaningful changes. There is a further risk of 'involvement fatigue' with too many consultation initiatives that have little impact on service standards or profiles. A recent evaluation of the application of the social model of disability in the development of services for disabled people commissioned by Birmingham City Council concluded that:

> While we have been assured by many of the departments that they consult regularly with users in a meaningful way, that was not always the story we were told by disabled people. They often felt that consultations was tokenistic and even where there were well established user groups, only the 'chosen few' were consulted and that was usually to enable the Department concerned to do what it had already decided to do (Oliver and Bailey 2002: 19).

As a result of this report the council has formulated an Action Plan in order to improve the situation. Among the measures introduced is one to support the creation of a city wide Coalition of Disabled People and the development of a user controlled Centre for Independent Living (see www.birmingham.gov.uk).

One significant area for disabled people that reinforces their concerns is the assessment of eligibility for social 'care' services. Professionals control the assessment procedures although there is local variation in how these 'care' assessments are conducted. Nevertheless, user involvement has increased over recent years. Whilst this has been welcomed by disabled people and their organisations, it has also exposed the limitations

of the rhetoric of empowerment within a social 'care' environment that is subject to tight budgetary controls.

Decisions about access to assessments are often influenced by service criteria based on risk and budgetary concerns. In contrast, disabled people and 'carers' often have wider definitions of risk that practitioners are reluctant to accommodate (Davis, Ellis and Rummery 1997). The situation is exacerbated by a perception that disabled people can become 'victims' of the inter-professional rivalry associated with the health and social 'care' divide (Glendinning *et. al*. 2000). Additionally, there is a continued disregard or even ignorance of the social model of disability and independent living amongst front line 'care' staff (French 1994; Abberley 1995; Finkelstein 1998; Oliver and Sapey 1999). This has resulted in considerable frustration and dissatisfaction with the entire assessment process among disabled people (Maynard-Campbell and Maynard-Lupton 2000; Mottingly 2002; Rummery 2002).

4. Barriers to user involvement

Despite the growing emphasis on user involvement in policy and provision discussed above, meaningful participation by disabled people in health and social support services remains relatively small in comparison to the disabled population as a whole. What then are the main barriers to disabled people's involvement in social 'care' services?

i. Financial and organisational

Through the 1990s, there has been a growing emphasis on 'markets' and private sector practices in the provision of health and social support services. This trend is evident in both the statutory and voluntary provider sectors. The emphasis has been on securing 'economy, efficiency and effectiveness' (Exworthy and Halford 1999; Sanderson 1999).

Managers have relative operational autonomy but only within strict budgetary controls and performance targets. In such an organisational environment there is far less opportunity for partnership with disabled people. The formal commitment to consultation and the implementation of user led agendas has been overtaken by a contrary set of political and economic constraints. These prioritise explicit standards and quantifiable performance targets, efficiency in resource allocation, and managerial

control over the workforce (Braye 2000). As a consequence, user interests have been relegated in importance.

In disabled people's own evaluation of the experience of user involvement a variety of constraints have been identified. These range from too little time for meaningful discussion, little access to senior staff, the value of disabled people taking on the preparatory training of service users, and the need for clear guarantees of confidentiality and codes of practice on conducting business and monitoring outcomes. Concerns are also expressed that user representation is too closely regulated by managers (Fletcher 1995; Ross 1995). A further uncertainty surrounding user involvement arises where front line workers re-interpret organisational guidelines and policies in their day-to-day practice (May and Buck 1998).

User-led organisations consistently report that accessing and maintaining core funding is a major problem. Instead most funding is short term and, in the overwhelming majority of cases, limited to specific services and projects. Furthermore, continuity and further development is further threatened by current funding strategies that encourage competition from non-user-led organisations. The situation is exacerbated by the growing emphasis on formal and bureaucratic procedures by funding agencies (Barnes, Morgan and Mercer 2001).

Established non-user led agencies enjoy a distinct advantage over user-led organisations in the current social 'care' marketplace. They have been around longer, are mostly staffed by 'professional' service providers, and usually have larger reserves and access to far greater resources (Oliver 1996; Barnes and Mercer 2003). Moreover, many health service and local authority staff have difficulty distinguishing between user and non-user controlled organisations, or appear far more comfortable dealing with the latter (Bewley and Glendinning 1994; Lindow and Morris 1995; Glasby and Littlechild 2002).

At the individual level, the imposition of strict eligibility and assessment criteria for access to support services seriously undermines the notion of meaningful user participation and choice. Direct payments are cash limited. Once the cash ceiling is reached users are at risk of having their support withdrawn and may be relocated into a residential home.

ii. Professional

Professionals still exercise considerable power over disabled people's lives (Davis 1993; Morris 1994). Each profession assumes a language, a set of values and practices that privileges the practitioner. Hitherto, a clear division between the expert-provider and lay-user has reinforced their enhanced status. This is confirmed in the traditional individualistic, medicalised explanations of disability and associated models for training and practice (Begum 1996; Wates 1997; Oliver and Sapey 1999; Read 2000). It is also illustrated in the continued use of the word 'care' in respect of disability related services, although disabled people's organisations reject this approach as overtly paternalistic and dependency-creating (Morris 1993; Finkelstein 1998; Clarke and Marsh 2003).

A further problem for professionals is that their claim to expertise and self-regulation does not sit easily with user participation. All too often the end result is a range of initiatives in which user involvement is little more than tokenistic or seen as an exercise in user education:

> where agendas, dominated by professional or agency jargon, are confined to existing services or predetermined decisions in which their (user) experience is denied or minimised (Braye 2000: 21).

iii. Personal

These constraints must be placed within a physical and cultural environment that generally demeans impairment, functional limitations and presumed dependence. Consequently coming to terms with either congenital or acquired impairment is, for many people, a particularly traumatic experience. Additionally, disabled people have to deal with an all-pervasive form of institutional discrimination (Barnes and Mercer 2003). The consequential 'internal oppression' or 'psycho-emotional dimensions of disability' (Thomas 1999) all too often leads to lowered self-esteem and self-confidence, and a significant withdrawal from everyday social interaction (Reeve 2002).

Furthermore, despite recent developments in health and social services, most support for disabled people of all ages is provided by 'informal carers' (Barnes and Mercer 2003). Indeed, while much has been written on the relationship between the 'carer' and the 'cared for' from the perspective of the former, the potentially detrimental effects on interpersonal relations within the 'caring' relationship are far less researched (Morris 1993; Parker 1993).

iv. Good practice guides

Disillusionment and resentment beckons if user involvement is not carefully planned and implemented. General guides highlight a number of core questions that should be asked of managers intending to develop a scheme for user involvement. How committed are you? What are you main reasons for involving people? Do you have the necessary resources? Are key staff and groups in the organisation on board with this? What are the requirements to support user participants? Are you prepared to act on what they tell you? How will you deal with the change in the balance of power that meaningful involvement brings? (Baulcombe *et al*. 2001).

The mechanisms for identifying, training and supporting users for their involvement has led to the publication of a number of 'good practice' guides (Beresford and Croft 1993; Carter and Beresford 2000; Baulcombe *et al*. 2001). There is a consensus that progress is slow in convincing managers and professionals that user involvement is a social and political right not a privilege. There is also evidence of low awareness among managers and professionals of disabled people's support needs – such as wheelchair access, BSL interpreting, accessible documents, and the specific difficulties in reaching and keeping disabled ethnic minority group members (Turner *et al*. 2003). There has also been increasing recognition of the importance of appropriate training for service user involvement. Important aspects include: assertiveness/ 'speaking up' courses, guidance on decision making structures, negotiating skills, legal issues and rights under current legislation. It is also valuable to know what has or has not worked in the past or in other policy areas. At the same time, there has been a more grudging acceptance that staff training is also necessary and beneficial, particularly Disability Equality Training (Sergent and Steele 1998; Baulcombe *et al*. 2001: 31-36).

In summary, user involvement requires 'champions' throughout the organisation for it to flourish. It takes time to change people's thinking and deeply embedded processes and structures. User involvement also generates conflicts around what counts as knowledge in social 'care': as is evident in the distinction between users' views of good practice and evidence-based good practice (Beresford 2000; DoH 2000; Edwards 2002).

6. Policy and Research Implications

User participation and involvement is now an essential feature of health and social support service policy and practice. Since the rhetoric of enhanced 'consumer' involvement and/or the 'democratisation' of provision has political currency for both the left and the right, it is likely to remain so for the foreseeable future.

But for the rhetoric to become reality there needs to be substantive material and cultural change within the statutory and voluntary institutions that continue to predominate within the health and social 'care' sectors. Indeed, user-led organisations struggling to generate greater user involvement operate within a constantly changing environment over which they little control, and this makes for considerable difficulties in future planning and development. As this Review has made clear areas that would benefit from meaningful policy guidance and further user led research include the following:

- ❑ national and local variations in policy on user involvement;

- ❑ how statutory and voluntary agencies manage and distribute resources for user involvement, particularly decisions about core funding for user-led services;

- ❑ the impact of different forms of user involvement on priorities, quality and outcomes of social 'care' services;

- ❑ the character, variation and consequences of user involvement in care assessment processes for individuals and their families;

- ❑ user participation in discrete 'informal care' relations, including relationships with personal assistants and 'carers';

- ❑ mechanisms of accountability in user led organisations; and

- ❑ reasons for the contrasting levels of involvement among disabled people in user-led initiatives.

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British Council of Organisations of Disabled People.

- also available at: www.leeds.ac.uk/disability-
studies/archiveuk/index

Appendix 1: Literature Search Strategy

The following databases were accessed:

Web of Science
MedLine
CAREDATA
CEBSS
CINAHL
Cochrane Library
ASSIA
      Social Sciences Abstracts
      Sociological abstracts
LARIA
SIGLE
UK Data Archive
Internet [world wide web]
University of Leeds Library Search [for books]

Keywords

[the following keywords were entered on all the above databases]

Care Standards Act 2000
Carers and Disabled Children's Act 2000
Centre for Inclusive/Independent/Integrated Living

Community Care [Direct Payments] Act 1996
Consumer consultation/ control/ involvement/ led/ participation/
representation
Disability and consumers/users
Direct Payments
Direct Payments and disability
Health and Social Care Act 2001
Independent/integrated living
Joint Review Reports
NHS and Community Care Act 1990
Social care policy/services
Social care and disability
Social care services and quality
Social Services Inspectorate
User consultation/control/involvement/led/participation/representation

In order to locate the maximum number of studies, the search strategy varied according to the indexing rules of different databases. Both 'freetext' and thesaurus terms were utilised. There were no restrictions on the basis of methodology or methods. The initial trawl identified over a thousand records, but this included several hundred duplicates. In addition, many records were subsequently eliminated because they did not satisfy the key inclusion criteria: empirical evidence on approaches, methods and outcomes of user's involvement in social 'care' services at the local or national levels, with specific reference to disabled people (or those groups not otherwise excluded in SCIE's terms of reference for this Review). This led to the identification of 157 papers for reading and assessment, which were then reduced to a list of 58 for inclusion in the study.

Of these 58 papers that met the inclusion criteria, these covered 38 different studies. None of the projects identified adopted an experimental (randomised controlled trial) or quasi-experimental research design. Instead, all of the papers may be broadly classified as 'experiential accounts', based on unsystematic research/data collection (4), systematic survey research (45), and 'miscellaneous' (7). Not all papers examined both disabled user views on user involvement and the impact, if any, on service support outcomes.

Studies of the effectiveness of disabled people's involvement in social 'care' have utilised semi-structured questionnaires and interviews, rather than randomised-controlled, or quasi-experimental studies, but many may

be characterised as 'anecdotal' reports with little elaboration of how the evidence was gathered or analysed. For example, the literature is characterised by a reluctance to compare different forms of user involvement, discuss the choice of outcome criteria and measures, and wider aspects of their research design. Little attention is given to the relationship between different approaches to service organisation and the impact of any user involvement.

Overall, the evidence base for reviewing the impact of disabled user involvement on the quality of service support is neither extensive nor, where it does exist, particularly rigorous. Nevertheless, designing studies of the impact and outcomes of user involvement in service support raises complex methodological issues. Evaluation studies should explore not only service outcomes, but user priorities as well. There should be a greater focus on the support needs of different groups of users.

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Barnes, C., Mercer, G. and Morgan, H. (2000, 2002)
Barnes, C., Morgan, H. and Mercer, G. (2001)
Barnes, M. and Warren, L. (1999)
Barnes, M. *et al*. (1999)
Batty, D. (2001#)
Baulcombe, S., Edwards, S., Hostick, T., New, A. and Pugh, K. (2001#)
Begum, N. (1993+, 1996)
Bewley, C. and Glendinning, C. (1994)
Bignall, T. and Butt, J. (2000)
Bracking, S. (1993+)
Butt, J., Bignall, T., and Stone, E. (2000)
Carmichael, A., Brown, L. and Doherty, M. (2000)
Clarke, L. (2002)
Craig, G. and Manthorpe, J. (1999, 2000)
Dawson, C. (2000)
Davis, A., Ellis, K. and Rummery, K. (1997)
DCIL. (2003)
Evans, C., Carmichael, A. *et al*. (2002)
Glendinning, C. *et al*. (2000)
Goodinge, S. (2000)
Harrison, S. and Mort, M. (1998)
Hussein, Y., Atkin, K. and Ahmad, W. (2002)
Killin, D. (1993#)
Lakey, J. (1994)

Lindow, V. (1999)
Lindow, V. and Morris, J. (1995)
Maynard-Campbell, S. and Maynard-Lupton, A. (2000#)
Moore, N. (1995)
Morgan, H., Barnes, C., Mercer, G. (2001)
Morris, J. (1993, 1994)
Mottingly, R. (2002)
Oliver, M. and Bailey, P. (2002)
Parker, G. (1993)
Pearson, C. (2000)
Priestley, M. A. (1999)
Read, J. (2000)
Ross, K. (1995)
Rummery, K. (2002)
SCIL. (2003)
Shah, S. and Priestley, M. (2001)
Thomas, C. (1999)
Turner, M., Brough, P. and Findlay-Williams, R.B. (2003)
Wates, M. (1997)
Witcher, S. *et. al.* (2000)
Zarb, G. and Nadash, P. (1994)

Key: + Unsystematic; # Miscellaneous; all others systematic survey research

Journals in the University of Leeds Library

[the following journals (2000-2002) were accessed]

Disability and Society
Findings (JRF)
Health and Social Care in the Community
Journal of Social Policy
Social Policy and Administration

The following websites were accessed:

http://www.southamptoncil.demon.co.uk

http://www.cilbelfast.org

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http://www.disabilityuk.com/masterpages/disab1.htm

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