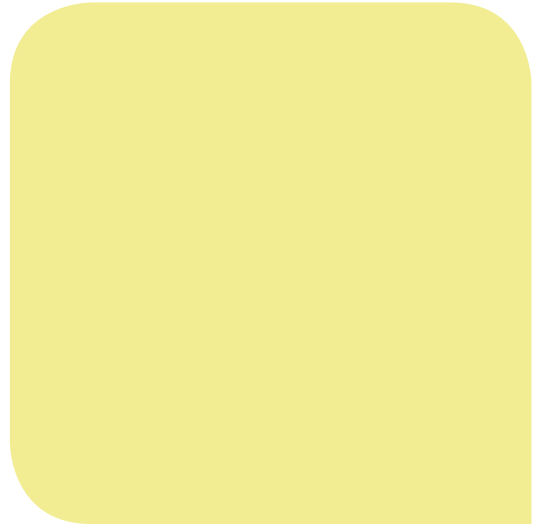


Developing social care: service users driving culture change



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Shaping Our Lives, National Centre for Independent Living and
University of Leeds Centre for Disability Studies

**Shaping
Our Lives**



First published in Great Britain in November 2007
by the Social Care Institute for Excellence

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Written by Shaping Our Lives, National Centre for Independent Living
and University of Leeds Centre for Disability Studies

This report is available online
www.scie.org.uk

Social Care Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB
tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
www.scie.org.uk

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Acknowledgements

We would like to thank all those who contributed to the production of this report. In particular we would like to thank the many organisations that responded to the initial questionnaire, the groups who were selected for more in-depth focus interviews, the steering group, and Laura Luckhurst and Michael Turner who spent many hours analysing the responses provided. We would also like to thank Sandy Marshall for her coordinating role and Sue Bott for overseeing the final stages of the report.

Definitions

Service user

This definition was developed by a diverse group of service users working on different projects with Shaping Our Lives.

What we mean when we say ‘service user’: Shaping Our Lives National User Network sees ‘service user’ as an active and positive term that means more than one thing. It is important that ‘service user’ should always be based on self-identification. Here are some of the things we think it means:

- It means that we are in an unequal and oppressive relationship with the state and society.
- It is about entitlement to receive welfare services. This includes the past when we might have received them and the present. Some people still need to receive services but are no longer entitled to for many different reasons.
- It may mean having to use services for a long time that separate us from other people and that make people think we are inferior and that there is something wrong with us.
- Being a service user means that we can identify and recognise that we share a lot of experiences with a wide range of other people who use services. This might include, for example, young people with experience of being looked after in care, people with learning difficulties, mental health service users, older people, physically and/or sensory impaired people, people using palliative care services and people with drug and alcohol problems.

This last point about recognising our shared experiences of using services, whoever we are, makes us powerful and gives us a strong voice to improve the services we are given and to give us more control and say over what kind of services we want.

What people sometimes mean by the term ‘service user’: The term ‘service user’ can be used to restrict your identity as if all you are is a passive recipient of health and welfare services. That is to say, that a service user can be seen to be someone who has things ‘done to them’ or who quietly accepts and receives a service. This makes it seem that the most important thing about you is that you use or have used services. It ignores all the other things you do and that make up who you are as a person. This is *not* what Shaping Our Lives National User Network means when we talk of ‘service users’ (Shaping Our Lives, 2005).

Professional

For the purpose of this work, the term ‘professional’ has been used to identify people who are in paid employment. This is regardless of whether or not they have a recognised qualification or whether indeed they self-identify as service users.

User-led organisations

For the purpose of this work, the term ‘user-led organisations’ are that the majority of the management group and/or people controlling the organisation are defined/self-define as disabled people/service users.

Executive summary

Background

SCIE commissioned NCIL, Shaping Our Lives and the University of Leeds to look at service user-driven culture change. The objective was to research current literature and practice around service user involvement, the extent to which service user involvement had brought improvements to social work and social care and where the change had become established practice.

Scope

The research was split into two areas: the research review that was conducted by the University of Leeds Centre for Disability Studies and the practice research that was jointly conducted by Shaping Our Lives and NCIL.

The research review concentrated on a wide range of service users, including:

- children and families in need
- fostering and adoption service users
- older people
- people with learning difficulties
- mental health service users/survivors
- people with a sensory impairment
- people with a physical impairment
- service users from black and minority ethnic (BME) communities
- drug and alcohol service users
- homeless people
- carers.

A questionnaire (see Appendix C) was developed in respect of the practice research and user-led organisations were targeted and were asked a range of questions regarding service user involvement and cultural change.

From the analysis of the returned questionnaires a range of focus groups were selected on the basis of their responses, including:

- older people
- people with learning difficulties
- disabled people
- parents and children
- mental health service users/survivors.

From these groups a further questionnaire (see Appendix D) was developed to find out information from professionals about service user involvement and where cultural change had occurred.

Key themes and findings

User involvement as a continuing priority

The theme of user involvement as a continuing policy priority for service providers and for service user organisations is one that comes through strongly in both the research review and the questionnaire and interviews carried out for the project. However, the review noted that current practices limit the effectiveness of user involvement and mean that the pace of change is slow.

Barriers to participation across the different types of services

Differing priorities and unequal power relationships between service users and professionals were a key barrier identified in the research review. Relationships between organisations and individuals were found to be a key issue in the focus group interviews, particularly where equity was an issue.

Differences in experience across different types of service users

There appeared to be a wide variation in levels of involvement between types of service users with some of the more seldom heard groups often absent from involvement. This may warrant further investigation. Experiences by service users ranged from tokenism to true partnerships.

Cultural change and resource issues

The research review identified funding and resources as a key issue, and the focus group interviews and questionnaires raised this as a crucial issue. In one area performance indicators were suggested as a tool to measure the continuation and development of service user involvement.

Cultural change as a long-term issue

The research review identified user involvement and participation as a key to change and the questionnaires and interviews carried out for the project offer a wealth of examples of ways in which this has happened. Examples include new schemes and services set up as a result of what service users identified as what was needed and appropriate.

The key message for practice from the project is that cultural change and service user involvement are inherently linked. Improving the practice around user involvement at all levels – which is cultural change in itself – is the key to improving change in all other aspects of service provision.

Introduction

The Social Care Institute for Excellence (SCIE) commissioned three organisations that formed a partnership for this work, Shaping Our Lives, the National Centre for Independent Living (NCIL) and Leeds University Centre for Disability Studies. All three organisations are committed to greater service user involvement in the development of social care.

The aim of the project was to look at how service users and user-led organisations have brought about changes and improvements to social work and social care. Such changes should lead to service users achieving the outcomes they want in their own lives, particularly in the areas of choice and control over their lives. The project was particularly interested in examples where change was sustained over a period of time and where service users influenced services delivered by the statutory and voluntary sectors.

The key issues for this research are:

- how policies work in practice to promote choice, independence and control;
- how service users can change or have changed and influence the work of service providers;
- how changes can be (or have been) embedded in organisations or institutions, their structures and processes;
- what service users and their organisations need in terms of support and resources to continue to play their role.

Literature review

2.1 Introduction

Involvement of service users in public services has become an important issue in recent years, and a large volume of literature on the subject has been generated. There are two main reasons for this. Firstly, increasing criticism of services by people using them has been voiced over a number of years resulting in an increased pressure for influence over the shape and nature of services provided. Disparities between what service users want and what is provided have been documented by a plethora of studies.¹⁻³

Secondly, government policies have prioritised a greater say for service users in public life. As well as a means of limiting the control exercised by professionalised services, participation is seen as a way of developing 'social capital', revitalising interest in voting in elections and joining political parties. User involvement, from a policy point of view, is considered to be a way of increasing electors' commitment to participative democratic processes.

Therefore although there is agreement about the desirability of user involvement, there are different reasons and priorities for putting it in place. Government policy also takes a broader view of user involvement than that commonly described by local authorities. The latter emphasises involvement in already existing public services, while national policy considers a broader involvement in civic life.

A whole raft of legislative measures has been introduced to support government policy. For brevity, most of these have been omitted in this research review.

2.2 Methodology

This section provides an account of how the literature search was carried out for this knowledge review.

2.2.1 Research questions

The literature search was driven by the following main research question:

Have social care services overall developed in ways that increase service user participation and experience of service improvement, and if so, how has this been achieved?

A number of subsidiary questions underpin this, as follows:

- How have policies aimed at enabling people to have more independence, choice and control over their own lives been realised?
- How have people using services led the process of defining desired outcomes, designing preferred solutions and bringing about sustainable change?
- Has there been an increased flexibility of service provision and practice that has provided personalised responses to individuals and families, and how has this been done?
- Have barriers preventing access to mainstream services and to effective interdisciplinary working been overcome, and if so, how?
- What has been the role of social work with regard to new policies, social care frameworks and changing public expectations?
- Is there evidence of sound and sensitive monitoring of outcomes and financial management?
- Have service user-led organisations been assisted to develop capacity and sustain good practice?
- What success factors have been identified by service users and other stakeholders with regard to the above?
- How might success factors be transferred across user groups?
- How might leadership development and the use of various organisational models build capacity for user-driven forms of practice and provision?

2.2.2 Sources of material

The literature reviewed includes service users' accounts, systematic reviews, empirical academic and non-academic studies, evaluation, audit and inspection reports, policy documents and parliamentary proceedings. Sources accessed include databases, search engines, books, journals and internet sites.

2.2.3 Search strategy

Both general (across user groups) and specific literature on service user-driven change was reviewed. Specific searches were conducted for the following groups:

- children and families
- fostering and adoption service users
- older people
- people with learning difficulties
- mental health systems users and survivors
- people with a sensory impairment
- people with a physical impairment
- service users from black and minority ethnic (BME) communities
- drug and alcohol service users
- homeless people
- carers.

For electronic searching, terms concerned with user-driven culture change were used. Keywords were tailored to those used by particular databases and search engines and the following were used:

- user involvement/user participation/user consultation/inclusion/representation/client relations/
- user-led/user control*/
- service change/service management/service culture change/service development/service improvement
- consumer choice/patient choice
- empowerment

- independent living/inclusive living/integrated living/direct payments/individual budgets/
- homeless/drug user*/alcohol user*

For some user groups, in particular homeless people and drug and alcohol service users, the search revealed no results. In these instances searches were carried out using the keywords 'homeless*', 'drug user*' and 'alcohol user*'. Because of the lack of relevant information here, more use has been made of articles from websites and non-peer reviewed journals.

Limitations placed on the search were as follows:

- The literature reviewed ran from 2003-06. Carr⁴ has compiled a thorough review of the main issues concerning change management and service user involvement up to 2003 and this review builds on her work.
- Social care as used here refers to services run by local authorities rather than the National Health Service (NHS). Obviously service users use a range of different services. A further issue here arises from the literature: unhelpful administrative boundaries may present barriers to some people and therefore the definition of social care has been used loosely.
- The review includes literature on direct payments and other forms of individualised funding, as examples of service change and development that have been led by user groups, even where they are not explicitly part of local authority provision.
- The emphasis is on direct involvement: studies concerned with user involvement in training and research have been omitted. These are important areas of work but the link to organisational change is not established in these studies.
- There has been a conscious attempt to prioritise the voice of service users in this review and because of this the criteria for inclusion are lower in some instances. For example, literature on the involvement of drug and alcohol service users and homeless people has been included on the basis that involvement is mentioned, rather than implemented. Issues of criminalisation that mitigate against self-identification and lack of resources of homeless people have contributed to the sparse developments here.

- It is important to note that academic definitions of what constitutes knowledge does not automatically map onto service users' understandings. It is also the case that service users often do not have easy access to such things as academic outlets and journals to publish their work. For these reasons, in this review there has been greater reliance on material sourced from internet websites (used more extensively by service user organisations) and less emphasis on academic publications.
- Only English language sources have been accessed.

Databases searched

AgeInfo
 ASSIA
 Economic and Social Research Council
 Ingenta
 Social Care Institute for Excellence
 Social Care Online
 Social Science Information Gateway
 Social Work Abstracts
 University of Leeds Disability Studies Archive
 Web of Science

Hand-searched journals

Adoption & Fostering
Ageing & Society
Critical Social Policy
Disability & Society
Findings (Joseph Rowntree Foundation)
Foundations (Joseph Rowntree Foundation)
Health & Social Care in the Community
Journal of Applied Research in Intellectual Disabilities
Journal of Social Policy

Websites consulted

See 'References' for a full list of websites consulted.

Results from the search numbered over 1,500, of which many were duplicates and therefore eliminated. Many publications and articles concerned guidelines on how user involvement should be implemented and because this literature has been covered previously,⁴ it has been omitted unless it discussed organisational change. Other literature identified was excluded on the following grounds:

- studies concerned with the benefits of involvement for service users rather than organisational culture change as a result of user involvement;
- areas covered fell outside the remit of the review, for example, patient involvement in NHS treatments, training or research;
- some authors wrote up their studies several times for different journals, for example, for a theoretical and a practitioners' journal. Where this occurred the article using the most relevant data to the questions, and that which matched the questions more exactly, was used;
- studies related to other countries;
- studies that fell outside the time frame.

2.3 Legislation and policy development

2.3.1 England

Direct payments legislation has been significant in giving service users more control over the services they use. The 1996 Community Care (Direct Payments) Act, implemented in 1997 in England and Wales and a year later in Northern Ireland, gave local authorities permission to give money to disabled people and people with learning difficulties who were under the age of 65 in lieu of services that they were assessed as eligible for under community care provision. The age restriction was removed in 2001. Carers and families with disabled children and children aged 16-18 also became eligible⁵ and since 2003 local authorities have been mandated to offer direct payments to applicants, providing eligibility criteria have been met.

Expansion of direct payments has remained a key government priority and a target has been set for the development of local support services based on Centres for Independent Living (CILs) in each area by 2010.⁶ The measures should, however, be seen in the light of competing demands on resources. Local authorities are required to balance their budgets and additional funding has not been made available to implement the provisions of the Acts and policy measures. Consequently, services are increasingly directed at supporting people deemed to need the most assistance.⁷ Implementation of direct payments has been slow and the fact that it remains a low priority for local authorities 'has led to calls for direct payments and the assessment process it rests on, to be removed from their control in favour of centralised, independent administration'.⁸

Working with local authorities has often been viewed ambivalently by disabled people's organisations because of the challenge to independence that this has often entailed⁹ as well as the lukewarm reception that service users have often received.⁴

Other legislation impacting on social care developments includes the Disability Discrimination Acts (1995 and 2005), which have conferred powers on the Disability Rights Commission to work for an end to discrimination and to promote equal opportunities for disabled people.

European legislation has provided the impetus for the Human Rights Act (1998), which makes it unlawful for public authorities to breach the European Convention on Human Rights, unless an Act of Parliament prevents them from doing so. Key measures include the right to life, prohibition of torture and inhuman and degrading treatment, the right to liberty and security, the right to respect for private and family life, and the right to marry and start a family.

Another large body of recent legislation concerns children and young people. Measures both offer protection to children and seek to control behaviour. The Adoption and Children Act (2002) places a duty on local authorities to consider children's needs and puts in place procedures for assessments, service planning and oversight of adoption services. The Children Act (2004) established a children's commissioner with the aim of safeguarding children's well-being and freedom from neglect and harm. It includes the duty to recognise the contribution that children make to society. Measures to control children's behaviour are seen in the

Anti-Social Behaviour Act (2003), where provision is made for parenting courses and dealing with weapons, among other measures.

The Carers (Equal Opportunities) Act (2004) places a duty on local authorities to inform carers of their right to an assessment of need. In carrying out assessments, local authorities should take into account whether the carer works or wishes to work, or to do any leisure activity. The Health and Social Care Act (2001) placed a duty on health services to consult people affected about planning, service development and proposals for change; this did not extend to social care. However the Act did make provision for direct payments to children aged 16 and 17, to carers and to family members.

The Homelessness Act (2002) gave local authorities the duty to formulate a strategy for homelessness, with a view to prevention and securing accommodation for people needing it.

In considering this range of legislation it should be borne in mind that several measures were affected by later amendments and Acts. Consequently they are works in progress.

2.3.2 Wales

The National Assembly for Wales was set up following a referendum in 1997 when it was approved at the time by a narrow majority of 50.3% to 49.7%; there are indications now that its popularity has grown within Wales (see the Economic and Social Research Council [ESRC] Research Programme on Devolution and Constitutional Change: www.devolution.ac.uk). Arrangements are complex and there is not a neat split between devolved powers and those held by Westminster. The Welsh Assembly may act where it has the power to do so, but has to lobby Westminster for other matters. Welsh policy therefore overlaps with English policy; however, it is becoming more autonomous, with the potential for policy differences to emerge in the future:

Whereas competitive models appear at first sight to offer the public service user more choice, in practice it is the management team who are empowered by it.... Such models exclude the empowerment of the public service user in the design of the delivery system. There is a perfectly respectable case to be argued for this model, but not for Wales.¹⁰

In *Wales: A better country*¹¹ a programme of changes is set out that forms a plan for action across a number of strategic areas. Commitments include improving public services through greater financial investment, economic regeneration and supporting improved health. Resources are identified to put this into operation. Allied to this document, *Making the connections*¹² and *Delivering the connections*¹³ put service user participation at the fore of service improvement, although here there is a less certain commitment to new resources: the emphasis is on re-design of services to ensure increased efficiency, particularly in later documents.

2.3.3 Northern Ireland

Policy development in Northern Ireland has been affected by recent social and political history, in particular ‘The Troubles’ that characterised the latter half of the 20th century.¹⁴ McLaughlin¹⁵ notes that social policies have been delivered at arm’s length, welfare professionals have held a stronger position in comparison with other UK countries and there has been a weaker culture of citizenship and social rights. Consequently user-led service change has made less headway here.

Northern Ireland developed a positive equality duty before England and Wales. Under Section 75 of the 1998 Northern Ireland Act (Appendix A), public authorities are required to have due regard to the need to promote equality of opportunity between people of different religious beliefs, political opinions, racial groups, age, marital status or sexual orientation; between men and women generally; between disabled and non-disabled people; and between people with dependants and people without. Reducing community divisions is an important issue and the need to change attitudes figures highly in policy literature.

The Equality Commission for Northern Ireland (2004-05)¹⁶ charts areas of progress on Section 75, particularly with regard to ‘race’ and disability, but also urges that further significant progress be made on most of the stipulations, especially sectarianism. There are several problem areas with regard to consultation. McLaughlin and Faris¹⁷ identify a shortage of resources, expertise and capacity among the community and voluntary sector. Second, there is not enough feedback on the results of consultation and understanding of the relationship between the content of consultations and subsequent decision making. Third, they describe instances of inefficient and wasteful use of community and voluntary sector capacity.

Fourth, there is some unrealistic expectation on the part of consultees about the place of consultation and equality considerations within the total decision-making process. Fifth, there are structural differences in Northern Ireland in that health and social services departments have been integrated without the involvement of local government. Further reform of structures is to be implemented: five new health and social services trusts will replace the 18 existing bodies and responsibility for these will be transferred to local authorities. A new Patient and Client Council will have the remit of promoting public involvement and providing advocacy services among other functions. This therefore represents a departure from an arrangement that has typically been characterised by exaggerated systems of dominance, subordination and inequality,¹⁵ as shown, for example, in the statistic that while 17% of people had experienced discrimination or harassment from public authorities in the past three years, only 31% had brought a complaint.¹⁸

2.4 Good practice

With the increasing requirements to incorporate user involvement into many areas of public life, there is an abundance of advice as to what constitutes good practice. This section discusses user participation in social care services, both in terms of user involvement in existing services and with regard to the setting up and running of user-led services, that is, services where service users constitute a majority.

2.4.1 Involvement in social care services

User involvement has been incorporated into a myriad of legislative and guidance measures over recent years and it is present in almost every area of public policy legislation. The provisions have not been very prescriptive, however: it has largely been left to local authorities and other organisations to decide how to interpret the measures.

Much good practice has been identified through noting what has not worked in practice. As Carr⁴ points out, bringing service users into existing services, without changing the nature of those services, does not automatically bring about change:

Power issues underlie the majority of identified difficulties with effective user-led change. User participation initiatives require continual awareness of the context of power relations in which they are being conducted. Exclusionary structures, institutional practices and professional attitudes can still affect the extent to which service users can influence change. It appears that power sharing can be difficult within established mainstream structures, formal consultation mechanisms and traditional ideologies.

The Audit Commission¹⁹ has outlined some of the principles of successful consultation with service users and provides examples of good practice in a number of areas. They suggest that commitment and culture are important: prioritisation of service users' needs should be part of the organisation's approach, resulting from a genuine commitment to make connections with communities. Management directives and statutory requirements are frequently insufficient in effecting change. Therefore user involvement needs to be effectively planned and managed and services need to be responsive to users. Good practice guides emphasise that people at all organisational levels need to be committed to the process. 'Champions' are needed to make the consequences of involvement stick²⁰ and it takes time to change thinking, deeply embedded processes and structures. As Barnes et al²¹ point out, 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.

Some people are more likely to be left out, such as BME service users²² and carers who are in same-sex relationships, who may fear hostile staff attitudes.²³

While consultation is a fairly rudimentary level of involvement, it may frequently be experienced as tokenistic, or reduced to the giving of information about decisions that have already been made. Good practice guides emphasise the importance of delineating what service users may expect from their participation and the limits of it. Young people in particular have often complained that they do not get to hear of the outcomes of their involvement or to see what difference, if any, it has made.

Other aspects of good practice have to do with practical arrangements. Service users are increasingly involved in meetings where decisions are made and those involved have pointed out the need for accessible venues, timing, materials and documents, all of which have been frequently problematic. Consideration needs to be given to particular requirements, such as replacement assistance so that carers can attend meetings, materials presented in particular formats and so on. Informal processes are also important in that service users need to be made to feel welcome and that their input is valuable. Finances are often a consideration for service users and costs of participation should be met.²⁴ Involvement needs to be inclusive, with particular efforts made to include groups who are not often asked.

Training for service users, in assertiveness, negotiation, meeting and committee procedures and legal rights are other practical elements of good practice here. Staff training is also necessary, particularly in such things as disability equality.²¹

Most good practice guides emphasise that cultural change should be the outcome of participation. Robson et al²⁰ distinguish between 'management-centred user involvement', where service users take part in existing structures and organisations determine the content of the meetings, and 'user-centred user involvement', where service users' objectives and priorities became the organisation's objectives and priorities. The findings suggest that users would only really value 'user-centred user involvement'.

2.5 User-led services

Because of the slow and uncertain pace of change, there is a growing emphasis by several user groups on user-led organisations. These are organisations where service users control management. The overall strategy here is to replace existing services with those that are more responsive to the needs of users. The importance of peer support has been recognised in the statement that:

By 2010 each locality (defined as that area covered by a Council with social services responsibilities) should have a user led organisation modelled on existing Centres for Independent Living.²⁵

Direct payments are more widespread in areas where there are user-led organisations and particularly so where local authorities support developments.^{26, 27} Where contracting authorities and user-led organisations work together, services are more effective.^{20, 28} The Joseph Rowntree Foundation²⁹ also states that ‘services cannot enable people to achieve their aims and aspirations without the full involvement of service users’. Finally the Association of Directors of Social Services and NCIL have issued a joint protocol recommending to local authorities that they support the development of user-led support organisations,³⁰ noting that 7 out of 10 of the top performing local authorities on direct payments contract with user-led organisations.

Although there are similarities in developments in England, Wales and Northern Ireland, there are also important differences. This section discusses some of the variations in service user-driven culture change and policies.

2.5.1 Issues in Wales

Mental health

There are a number of documents that set out the Welsh Assembly’s commitment to mental health service users’ involvement in services.³¹⁻³³ Requirements are for local authorities to provide mental health service users and carers with comprehensive, clear and timely information. Meaningful involvement of service users and carers in all aspects of service development, including planning, design, implementation, monitoring and evaluation, is also stipulated. Organisations such as health boards, NHS trusts and voluntary organisations are urged to work together to support these ends.

Areas of good practice are reported, such as instances where staff were recruited using two autonomous interview panels, one of service users and the other of managers, with neither group allowed to overrule the other and arriving at a consensus.³⁴ However, there is also evidence of the persistence of barriers, notably from service staff who are reluctant to change, difficulties with lack of resources, timing of meetings and tokenistic involvement. Attitudes were also the subject of a study by Soffe et al,³⁵ who reported that clinical psychologists, while generally supportive of user involvement, also expressed concern that successful involvement

depended on which service users were involved, despite their awareness of the need not to be tokenistic. Some were also concerned that service user involvement might reduce or remove the need for psychologists in mental health services.

Disabled people

The Welsh Assembly Government adopted the social model of disability as the basis for its work on disability in 2002 and provides details of joint work being carried out with Disability Wales, a national pan-disability service user-led organisation that promotes the social model and user involvement in public life. However, a Disability Rights Report cited in Disability Wales News concluded that the Assembly was not in a position to fully implement the social model at that time.³⁶ Despite this, Disability Wales reported on a joint project with the Disability Rights Commission to develop the capacity of local access groups across England and Wales³⁶ and reported on continuing collaboration with both the Disability Rights Commission and the Welsh Assembly Government.

Children and young people

The Welsh Assembly Government published the results of a widespread consultation with children and young people in Wales for the purpose of developing a National Service Framework.³⁷ The main message for social care services was the need to keep promises, to listen and to be honest: 'Lots of participants felt that more could be done by adults to treat young people with respect and to acknowledge young people's right to be involved in their care/provision'.³⁸ Turner's consultation³⁹ with disabled children identified staff attitudes and behaviour, information provision, access and availability of services (especially transport), choice of services and participation in decision making as particularly problematic.

Despite some progress with regard to looked-after children, Payne et al⁴⁰ note a widespread lack of reporting on involvement from service providers and recommend that reporting and monitoring be increased.

People with learning difficulties

Planned improvements to services for people with learning difficulties include information provision, support for advocacy, service planning, community living, employment, health and joint working.⁴¹ All Wales People First⁴² set out priorities in terms of rights to control their own lives, to speak up for themselves, to respect, to personal growth, to be included in the same activities as everyone else and to friendships and personal relationships, as well as the right to choose how and where they live, to good quality healthcare and to good quality support. There are similarities in the two accounts; however, All Wales People First places more emphasis on outcomes and decision making.

All Wales People First also provided a report commissioned by the Welsh Assembly Government, 'Fulfilling the promises',⁴³ an update to the All Wales People First Strategy.

Carers

Wales Carers Alliance⁴⁴ sets out key demands as follows: time off from caring, free services, choice of support services, a duty on political parties to inform carers of their rights and ensuring that NHS and local authority services know that support for carers is a key service requirement. They note that there are over 350,000 carers in Wales and that their unpaid contribution saves the Welsh economy at least £3.5 billion every year. Income poverty is highlighted by Contact a Family Cymru,⁴⁵ who urge measures such as inclusion in childcare for disabled children, assistance with benefit take-up and debt advice and work with employers to assist with work–life balance.

Wales Carers Alliance⁴⁶ reported that while 90% of carers in their survey appeared eligible for an assessment, only 38% had received one and just 50% were informed of their right to one. The report recommended training for social workers to rectify this. Carers were also underrepresented as recipients of direct payments.⁴⁷

Black and minority ethnic service users

The Welsh Assembly Government has estimated that the population of BME people in Wales in 2001 was 61,576 and estimates an increase to

91,269 in 2011 making up 3% of the total population of Wales. Despite the increase, access to services from BME people is relatively low. Similar issues to those in England have been identified that there is a perception that people 'look after their own' and there are also language and cultural barriers.

Drug and alcohol service users

The National Assembly for Wales⁴⁸ reports inequalities in terms of people's ability to access the range of services across Wales and notes that offenders may be in a better position to access services than non-offenders. Several treatment services in Wales are not accessible to people with mobility problems. Further concerns expressed have to do with the willingness of general practitioners (GPs) to treat drug and alcohol service users, accommodation issues, public opposition to treatment services and their development and the collection and use of information.

Service user involvement is at a very early stage of development. Initiatives by service providers largely take the form of asking people to contact treatment providers to comment on the services received from them.

2.5.2 Issues in Northern Ireland

With widespread curtailment of civil rights during the years of hostilities, service user movements have remained relatively undeveloped. Nevertheless a limited literature on this exists for the dates of this review.

The Bamford Review is a wide-ranging review of the law, policy and service provision in Northern Ireland that began in 2002 and that has not yet completed its task at the time of writing. It originated from the need to update legislation concerning mental health service users and people with learning difficulties in the light of other UK and European measures. With Northern Ireland mental health legislation over 20 years old (1986 Mental Health Order), the Human Rights Act (1998) and Disability Discrimination Act (1995) have given impetus to reforms.

A larger proportion of the mental health service users and people with learning difficulties receive services that are hospital-based compared with other parts of the UK: community services remain relatively

under-developed. The intention is that Service Frameworks, much like those in existence in England and Wales, will result from the work of the committees and that standards for commissioning and targets for measuring progress towards social inclusion will be set.

Service user involvement has been an explicit part of committee processes and is emphasised in the content of the reports, both in terms of involvement in developing the nature and shape of services and involvement in services individuals receive. Committees have taken a broad perspective and children, young people and adults are included. Reports consider mental health service users as well as people with learning difficulties, drug and alcohol service users from minority cultures and those subject to the criminal justice system. Additional reports also make recommendations for people with learning disabilities and autism/Asperger's syndrome.

The Bamford Report may be seen as an example of 'read across' service development¹⁵ in that the stipulations are very similar to policy concerns in England and the methods for monitoring progress that are advocated bear marked similarities. As a wide-ranging and exhaustive piece of work it may be expected to have some significant impact and has attracted cross-party support.

Mental health

The Bamford Review⁴⁹ sets out a strategy for mental health services that is based on valuing people with mental health needs, rights to full citizenship and equality of opportunity and self-determination. The stated intention is the modernisation of services that will make a tangible difference to the experiences of mental health service users and their families.

The Review found that Northern Ireland had significantly higher levels of mental ill health in comparison with other areas of the UK. The legacy of violence and civil disruption on the population has been held to account for this, as well as the impact of unemployment and deprivation. Inequalities in mental health have also arisen through social factors such as poverty, discrimination, isolation and poor housing and also because of discrimination on the basis of age, ethnic minority, gender and sexual orientation.^{50, 51}

User involvement in service design was found to be inadequate and services unsatisfactory, with only 30% of service users' need being met. A higher incidence of service users placed in hospitals was seen as due to a lack of strategy and vision on the part of service providers. A large number of recommendations (136) have been made including a large increase in expenditure, but at this point in time it is not clear whether funding will be forthcoming.

Disabled people

A cross-impairment organisation, Disability Action,⁵² has produced a comprehensive set of recommendations based on consultation with disabled people and their organisations. While the report covers a wide ground, two issues for health and social care are prioritised: health and well-being and equality of access to services. In particular attention is drawn to the need for disabled people to be represented in decision making during all stages of policy development and for independent advocates to be provided at service delivery panels involved in care planning, if disabled people so wish. Information is also problematic: signage, lack of interpreters and information in other appropriate formats are singled out for mention.

Medical intervention in non-medical matters is criticised and there is a call for resource realignment so that independent living is supported rather than losing out to the acute health sector. Disability Action further calls for more information about direct payments, access to up-to-date aids and adaptations and appropriate domestic support such as help with decorating and grass cutting.

More generally, there is criticism that social policy continues to be defined by a medical model of disability and it is recommended that policy should be underpinned by the social model and progress towards this monitored through annual independent assessment. Political and civil rights are also highlighted, and barriers to independent living such as inaccessible information and attitudes discussed. Consultation is also mentioned as a priority.

These issues are particularly pertinent because of the high rate of impairment in Northern Ireland: over one in five of the population, with a quarter of all families affected by disability.⁵³

Children and young people

Children have been involved in services to a greater extent than some other groups. Pinkerton⁵⁴ points out that young people have been working with the Children and Young Persons' Unit and that this had led to their involvement in the appointment of a commissioner. The Northern Ireland Assembly has also recognised the importance of involving children.

On the other hand, involving children and young people has been shown to be difficult. Bryson⁵⁵ reports on a project that involved children who had experienced serious effects of conflict. Due to their experiences young people were wary of saying what they thought, especially around strangers. In encouraging children to have a voice and become visible project workers ran into difficulties of challenging beliefs and attitudes. Children were fearful of speaking beyond the rigidities of sectarian politics and consequently youth work in the area remained fragmented, without a cohesive voice. Bryson concludes that there is still much to be done in terms of changing the context of children and young people's participation because the adult world cannot always accommodate their demands for feedback, time and information.

A more successful experience is reported by Willis et al,⁵⁶ who discuss their involvement in the children's services planning process. Young people were able to recruit others who in turn were able to speak directly to adult planners involved in devising their services, and they report that 75% of those attending a conference agreed to remain involved. In turn this led to the formation of reference group that could discuss issues with subcommittees.

People with learning difficulties

The report 'Equal lives'⁵⁷ sets out the key values of social inclusion, citizenship, empowerment, working together and individual support as the basis for its recommendations.

A higher number of people with learning difficulties currently live in institutions (hospitals and residential homes) in Northern Ireland than in other parts of the UK. In Northern Ireland over one quarter of people with a learning difficulty surveyed in the course of the Bamford Review lived in nursing homes. The proportion of nursing home places

is higher than in England and Wales, where in 1997, 7% of their places were in nursing homes. However, there is regional variation within Northern Ireland. The review notes that people with learning difficulties in Northern Ireland 'do not enjoy equality of opportunity and are often excluded from the opportunities that other citizens enjoy ... there is a need for major co-ordinated developments in support and services and a continuing change in attitudes over at least the next 15 years'.⁵⁸

It is notable that people with learning difficulties and family members were consulted during the course of the research. The authors also note that there are few formal organisations that represent the views of people with learning difficulties or family carers. Service users have rarely been involved in planning services. People with learning difficulties consulted in the course of the review highlighted concerns about housing, choice over who to live with, being listened to and respected, having access to advocacy and getting the same opportunities as others.⁵⁹

Carers

Parents with young children in Northern Ireland have reported dissatisfaction with the statementing process, particularly the length of time taken and their sense that concerns were not listened to.⁶⁰ Some parents reported that they were not informed about the processes that they and their children would go through and felt shocked when they learned of the impact that the statement would have on their child's access to education in the future. Other concerns expressed were that educational professionals often did not appear to know what advice or services to offer their children. Also of concern was that some children were only in special schools because mainstream schoolteachers lacked the skills needed.⁶⁰

Further issues raised have to do with adequate information, such as finding out about direct payments, and getting assistance so that carers could take breaks.

Black and minority ethnic service users

Reports of racially motivated incidents and crimes in Northern Ireland rose from 453 in 2003-04 to 813 in 2004-05, therefore showing a marked increase.⁶¹ Negative attitudes of a sizeable proportion of the population have been reported, particularly towards Travellers. However, there is also concern that while measures have been taken by many public

authorities to reduce incidents, issues of sectarianism have not been effectively tackled.¹⁶

The Racial Equality Unit⁶¹ suggests that the context for racism in Northern Ireland may be different from other places because of the existence of sectarianism that has created patterns of residential segregation and hostile attitudes.

Drug and alcohol service users

Northern Ireland has polarised attitudes to alcohol use in that while a large proportion of people voluntarily abstain, there are also large numbers who drink heavily.⁶² Although reported incidents of drug taking were lower during the time of 'The Troubles', levels have subsequently risen.

2.6 Forms of user involvement

Arnstein⁶³ proposes a ladder model for citizen participation and compares different forms of involvement. These range from non-participation (manipulation and therapy), through tokenism (informing, consultation and placation) to citizen power (delegated power and citizen control). Her influential analysis has been used in many of the studies reviewed here. Although some authors propose modifications to the model, all make some form of distinction between various forms of involvement on the basis of the degree of influence accorded to service users.

Another change strategy aimed at altering services is the independent development of user-led services, such as CILs.⁹ This overlaps with Arnstein's top rung of participation but a distinction may be drawn because many have developed from self-help organisations rather than as a result of involvement in public services. Increasingly user-led services compete for funding and contracts from commissioners but financial security is difficult to achieve while funding is tied up in the provision of traditional services, which may be short term, and while commissioners show a preference for larger, known providers.²¹

A third approach to organisational change may be seen in the political campaigning undertaken by user groups, where the intention is to change laws and structures through a 'top-down' approach to services. An example is the campaign for direct payments and individualised

funding, which took a political approach largely bypassing formal service structures in favour of legislative change. Here, change efforts are mostly independent of any service involvement. Again an issue remains that most financial resources are tied up in traditional structures. Exerting external pressure may be quicker, but ultimately resources need to be secured and it has been consistently acknowledged that working from inside services to change them through involvement may take considerable time, given vested interests of established providers and power differentials.

2.6.1 Studies on user involvement across user groups

Most of the literature on user involvement concerns service user involvement in established, local authority-run public services. There is a consistency in findings from research studies across a broad range of user groups and circumstances. This section considers some of the common themes.

Participation has been seen as the key to change in services^{22, 64} and 7% of users participate on an occasional or regular basis.⁶⁵ Some participate more than others: Young⁶⁶ points out that mental health service users, people with learning difficulties and older people are more likely to be involved than children and drug users, for example. Studies also consistently note that some groups such as BME service users, are much less likely to have opportunities to participate.⁶⁷

A number of problems have been repeatedly described. Firstly, influence may be limited because service users are often consulted on plans and priorities that have already been devised rather than involved in drawing these up in the first place. New services are frequently developed by people other than those who use them, and departmental fragmentation may not reflect the reality of service users' lives.⁶⁷ Rummery⁶⁸ points out that proposed mergers between health and social care organisations may not be successful due to the omission of service users' perspectives: partnership working is not automatically supportive of service user participation, and may deflect attention from it.

Carr⁴ notes that the priorities of service users and professionals may be different. Power relationships are unbalanced and service users may not be taken seriously. The issue of not being listened to in the sense of professionals not using the insights of service users is reported consist-

ently across studies, and is particularly acute in children's services. The Commission for Social Care Inspection⁶⁹ echoes these concerns, noting a number of reasons for the low take-up of direct payments, including patronising staff attitudes with regard to the capabilities of service users. Studies have highlighted the uneven development of direct payments provision and linked this to the broader political commitments of local authority policies.⁷⁰⁻⁷² Representation is also a frequently recurring theme, and the argument that service users who participate are not representative of a wider constituency have been used to discount contributions.

Other barriers to participation that reflect the unequal balance of power include the timing of meetings to suit providers rather than service users, the use of jargon, the structure of meetings as well as other interpersonal processes that inhibit the participation of service users.⁷³ Often participants have reported that they received no feedback on how their input had been used, or even if it had. Recommendations have included the need to acknowledge that service users may want to be involved in ways that fall outside the usual mode of service operations, and the fact that some may want to make more or less of a commitment. This is especially pertinent to groups of service users who may have less time, such as carers.

Conversely some authors present a more optimistic picture. Hasler,⁶⁴ in her study on participation on national boards, reports that the experience of user members was overwhelmingly positive in terms of the attitudes encountered. Birchall and Simmons⁶⁵ note that while many service provider respondents told them that they had involved service users because they were directed to do so by national government, they also reported benefits to their organisations and service provision. Organisations have reported that service users benefited as a result of their involvement, although Carr⁴ cautions that service providers should look beyond this, to using the expertise of participants. Beresford and Croft⁷⁴ call on social workers to develop a more emancipatory role by supporting the aspirations of service users.

There are many tensions in user involvement. One of these is the payment distinction between service users and service providers, which is coming under question. For example, Turner and Beresford²⁴ argue that involvement work should be paid and recommend changes to the benefit system, a relaxation of the rules surrounding 'permitted work'

and education for job centre staff as a means of dealing with barriers to this. The Care Services Improvement Partnership⁷⁵ has recently set out guidelines for expenses and other payments to service users undertaking involvement work, although detailed arrangements are not specified.

While the literature consistently discusses the barriers to involvement noted above, most support user involvement and consider it to be an essential means to service improvement. This may be seen in the large number of guides to implementation.⁷⁶ While a range of change strategies may be employed, the need to engage or deal with current provision remains an issue at some point in the development of responsive services. The literature is consistently clear about the limitations to effectiveness in terms of altering what services do within the current frame of reference: progress is slow, especially in instances where re-allocation of funding is required.⁷⁷

2.6.2 User involvement and different user groups

As well as the similarities discussed above, there are important differences according to user groups. These are discussed in this section. Many service user groups have their origins in the 1960s and 1970s, although others formed more recently or have been intermittently active. The groups described are obviously diverse with overlapping membership and some are universal in that membership is linked to the life course.

Mental health

The present mental health service users movement has expanded considerably in recent years. Collective action has been used to challenge the stigma of mental ill health, to campaign about the organisation of services and to provide self-help, support and advocacy. Researchers have documented over 300 active local groups, with a membership of around 9,000.⁷⁸

Rose et al⁷⁹ pinpoints the importance of process and organisational culture in sustaining user involvement in services. Change was most successful in instances where these 'soft' issues were combined with 'hard' measures (change in structures, systems and services).

The idea of service users as ‘customers’ has faced a particular challenge by the user movement because of the prevalence of restraint and coercion. Problems with ‘exiting’ services has led to a greater emphasis on citizenship rights.⁷⁹ Risk assessment procedures are of particular concern⁸⁰ and have been used to exclude service users from involvement.⁸¹ These issues also appear with direct payments, where service users may be deemed unable to manage arrangement.⁸² Over-representation of marginalised groups (BME groups, women and poor people) contributes to the potential pathologising of user views.

Rose⁸³ points to the increasing trend towards employment of users within services as a countering influence. While, as Arnheim notes, this can mean co-option of ‘troublesome’ elements, it may also serve to blur the boundary between service users and providers, improve the situation of service users and to develop services that are more attuned to service users’ needs.⁷⁹

Disabled people

Direct payments and other forms of personalised funding are an example of policy change that developed in large part from the efforts of disabled service users dissatisfied with prevailing forms of service provision. Initially pressure was exerted largely, although not wholly, through independent political campaigning rather than influence exerted on local services.⁹ Barnes et al²¹ point out difficulties involved in identifying user-defined outcomes, especially as these often extend beyond the remit of ‘social care’ responsibilities, requiring change in public services such as transport, employment, benefits and housing. However, they note instances where services have developed that are more in line with service users’ aspirations as a result of user involvement, despite a general lack of awareness among managers and practitioners about good practice in involving disabled people.

The Independent Living Movement has been a driving force for change and the establishment of CILs a key priority for supporting disabled people interested in or receiving direct payments. CILs have been shown to be important for the success of independent living and direct payments,^{27, 67, 84} and while a government commitment has been made to establishing a CIL in each locality, securing resources remains a large problem.^{8, 9, 67}

Children and young people

There is a growing volume of work concerned with the inclusion of children's perspectives, most of which has been written by adults.

Children and young people's participation has grown markedly in the past few years,⁸⁵ in response to UK government and international imperatives. Policy measures stipulate that children should have a say about neighbourhoods, education, health and social services. In practice the results have been patchy: Cutler⁸⁶ suggests the introduction of standards for participation as a means of addressing this. Government measures have set limits on participation by stipulating that Children's Fund partnerships must allocate 25% of their budgets to activities related to crime prevention and anti-social behaviour.⁶⁶ *Every Child Matters*⁸⁷ emphasises the need for children's services to work together to secure specific outcomes for children: being healthy, staying safe, enjoying and achieving, making a positive contribution and economic well-being. However, the targets attached to these emphasise going to school, avoiding negative behaviour and anti-social behaviour.⁸⁸

Children are more likely to emphasise the importance of safer streets, cleaner parks, and cheaper public transport and leisure facilities.⁸⁸ Other priorities include greater involvement in decision making in schools and being respected in shops and other public places.⁸⁹ There is therefore a gap between the priorities of government and children, and children frequently claim that they are not listened to and not respected.⁹⁰

An important part of the government agenda is the active engagement of young people in voting and in responsible behaviour. While children have been characterised as disconnected from political processes, they may prefer to participate in other forms of political expression such as demonstrations, boycotting products and signing petitions. Colman with Rowe⁹¹ argue that young people are not disaffected but switching the ways they prefer to engage with political processes.

Children's effectiveness may be limited by staff attitudes, meetings that are not child-friendly and inadequate preparation time. Staff turnover may also inhibit the formation of trust. These issues are particularly important for less advantaged children such as those who are looked after, who often lack information about care plans and about their rights with regard to services.^{92, 93} Children whose views are asked for but not acted on may become disillusioned.⁹⁴ Marginalised and younger chil-

dren are less likely to be involved than those who are more articulate and older.⁹⁵

People with learning difficulties

While people with learning difficulties have been involved as service users for longer than some other user groups, there is a tendency for this involvement to be seen as rehabilitative. A diagnostic label may lead to people with learning difficulties being seen as incompetent and excluded from involvement.⁹⁶ On an individual level, certain groups of people are less likely to be involved in such activities as person-centred planning, if also labelled as having mental health or behavioural problems, autism, health problems or restricted mobility.⁹⁷

Official policy is that people with learning difficulties should have a say about their lives, and this should be at all organisational levels. Service providers should listen to what people say with regard to advocacy, direct payments and individual budgets, person-centred planning and communications. Family carer networks should also be involved. Consultation with people with learning difficulties is via the National Forum for People with Learning Disabilities on a national level, and through partnership boards on a regional level.⁹⁸

Fyson and Ward⁹⁹ point out that partnership boards lack power. Service users also face difficulties participating due to problems of inaccessible information, physical access, and lack of reimbursement for travel expenses or loss of earnings, and the timing of meetings. These issues reflect the fact that user involvement here is on the terms of service providers.

User involvement is closely linked with self-advocacy and Beart et al¹⁰⁰ point out how confidence in making views known is strengthened by group membership. Dearden-Phillips and Fountain¹⁰¹ discuss the working of the Cambridgeshire Parliament as an example of participation on service users' terms. MPs are elected as representatives of particular constituencies and service managers invited to attend to discuss particular issues. Reported developments include the removal of a manager and training of GP receptionists on issues of concern.

Peer support has been shown to important for accessing direct payments but as yet there is little independent support run by and for people with learning difficulties.¹⁰²

Carers

Carers have been recognised more fully in recent government policy,^{103,104} but despite this, research has shown that carers feel unsupported by statutory services and are often unaware of their rights to assistance. Macgregor and Hill¹⁰⁵ report that despite new legislation many did not know about their right to assessment. Although carers expressed a wish for more support, the proportion receiving an assessment had risen from just 21% to 32% between 1997 and 2003. Dissatisfaction with rules forbidding direct payments for certain kinds of assistance was also noted. Lack of access to service support has been portrayed as a human rights issue on the basis that it inhibits inhuman and degrading treatment and rights to family life.¹⁰⁶

Roulstone et al²³ report that while local authorities and PCTs were trying to involve carers, and provide feedback on the difference this involvement made, commitments on paper did not seem to be translated into substantive changes. Where instances of changes were described, these tended to refer to procedural developments rather than specific outcomes. Issues raised in their report include services for gay and lesbian carers, support for carers to work and reaching carers who were marginalised. Time to participate in user involvement was also problematic for some.

Swain and Walker¹⁰⁷ discuss relationships between parents and professionals with regard to an education centre that had been set up by parents. While parents faced a battle to secure resources and felt their views were not listened to, professionals questioned the legitimacy of the centre and its clinical effectiveness. The authors doubt the possibility of establishing a partnership in this instance, concluding that power relations were a central issue of contention. While the omission of children's perspectives is commented on, Young et al¹⁰⁸ note in their study of physiotherapy services that professionals exercised most power in decisions, followed by parents and finally children.

Black and minority ethnic service users

It has been consistently shown that BME service users are less likely to be involved with services in a number of ways. Firstly, there is less likelihood of receiving support because of services users' lack of knowledge

about what is available. Secondly, services are often not appropriate in terms of what is needed: poor quality and lack of choice have been reported¹⁰⁹ as well as discrimination and stereotyping, mono-cultural service provision and discrimination within cultural communities.¹¹⁰ Particular issues concern more disadvantaged groups of BME service users. Refugees and asylum seekers are more likely to experience negative attitudes, language barriers and isolation. Patel¹¹¹ recommends that data is gathered to identify where and how many refugees and asylum seekers there are in each area and that specialist rather than generic workers should be recruited to do this.

Issues remain even with services such as direct payments, where there is more choice available with regard to the personnel involved and the way the service is delivered. Problems about the meaning of independent living for service users, with recruiting appropriate personnel and rules governing who may be employed, can compound the above problems.¹¹²

Shaping Our Lives National User Network¹¹³ similarly highlights the importance of both processes and outcomes for users in defining their own needs, experiences of discrimination and lack of respect from service workers. Where BME people do receive service support, they are less likely to be selected for involvement in consultative or decision-making capacities. Service user groups have tended to organise independently to represent their interests where cultural background and personal experience may be acknowledged.¹¹⁴

Drug and alcohol service users

The move to involve drug and alcohol users in services has been less marked than for other groups, although the expectation of involvement remains, through the Health and Social Care Act (2001). Part of the reason for lesser participation in service design is the criminalisation of drug taking and the stigma attached to excessive alcohol use. The main paradigm is prevention of drug use: there is an expectation that drug and alcohol services will change the behaviour of service users and for many professionals user involvement has been synonymous with participation in detoxification treatments. Involving service users is seen as a step towards the eradication of drugs and drug use.

Taking a different approach, the Harm Reduction movement is concerned with minimising negative health impacts on users and others and has called for a challenge to the merits of the drug prohibition strategy.¹¹⁵ Drug users have been more involved in this movement, as user groups share similar concerns.

However, a more radical international movement questions professional leadership and has called for a recognition of human rights, asserting the need to organise independently.¹¹⁶

Based on the views of service users, the European Association for the Treatment of Addiction¹¹⁷ provides a large number of recommendations for improving services while noting that opportunities for influencing services through direct involvement are almost negligible.^{118, 119}

In recent years there has been more discussion about involving service users and there are some reports that document where this has started to happen.^{120, 121} Details of two instances where service users were given small grants for specific projects are given by the Mayor of London/Greater London Drug and Alcohol Alliance.¹²²

Fostering and adoption

Fostering rather than adoption is of most concern in the literature. Fostering is treated as an extension of the formal care system for looked-after children, who may be in the system for a wide range of reasons, ranging from imprisonment following conviction of crimes, remand while awaiting trial, separation from abusers or for reasons of absconding from services.

The formal rights of children in foster care have been strengthened in recent years¹²³⁻¹²⁵ but there is a tendency for the government to focus on external inspection and service self-reporting rather than children's involvement. Thomas¹²⁶ compares self-reported changes from managers of children's services between 1997 and 2004 and states that managers in children's services are increasingly developing policies on complaints procedures, arrangements for looked-after children to meet one another and now increasingly delegate decisions to carers about whether children may stay over with friends. On the other hand, no development was reported on policies for involving children in decisions, on access to records or communication of policies. While children may be involved in more general matters of policy development, they are likely to have less say

with regard to their own care plans and circumstances, demonstrating that formal policies do not translate into changes in practice.

Continued difficulties were reported by Voice for the Child in Care¹²⁷ with regard to the conduct of formal case reviews. Issues include being allowed to speak, the possibility of having a friend or advocate present, choosing who attends rather than having strangers present, who chairs meetings and being presented with shocks and surprises. Other issues concern lack of respect, preparation and knowing what will be said. Disabled children reported assumptions that they would not be able to do things and decisions being made quickly, while non-disabled children reported lengthy delays and decisions being made too late for these to be helpful.

Carers for fostered children have consistently highlighted problems of lack of support from services. The main issues reported are lack of support from social workers when needed and financial insecurity. Foster carers tend to become more involved in conflict with statutory services over time and may either resolve this or leave.¹²⁸

This search was unable to find any evidence of a relationship between fostered/adopted children's involvement and organisational change in services.

Older people

As with other service user groups, policy measures have made the involvement of older people a requirement, intended as an equal partnership and not simply consultation. However, as Janzen and Law¹²⁹ note, there is little evidence that involvement has impacted on service development toward achieving the outcomes that older people want. Older people's priorities are reported as being: having good social relationships, help and support, living in safe and neighbourly places with good transport links, having hobbies and personal interests, enough money to meet basic needs, and having control over their lives.¹³⁰

Older people have pointed out that their lives are about more than health and social care. As such, there is a tension between a view within many services that older people are frail and dependent with the broader aspirations of elders. The Joseph Rowntree Foundation³ reports that an emphasis on government targets has militated against flexibility and responsiveness to service users, as person-centred approaches have been

shelved in favour of the pursuit of star ratings. The literature presents evidence that older people are being increasingly involved in services, despite reported barriers to participation,¹²⁹ but these appear to be changes in form rather than in outcomes for service users.

From another perspective, Postle et al¹³¹ consider older people's involvement in political activity, noting the development of pensioners' forums, many of which have grown from self-help groups. Often campaigns are about single issues, such as opposition to council tax arrangements and other public services such as health and transport. Postle et al present the argument that social workers ought to be supporting this form of participation.

Homeless people

Homeless people have yet to be involved to any great extent.¹³² Because people who are homeless may move around and have often, in common with drug and alcohol users, been characterised as having chaotic lives, their pattern of movement may not fit the administrative boundaries of service providers. Gaining access to services is again an issue, and having an advocate who will negotiate access to services may be helpful.¹³³

Anti-Social Behaviour Orders are of particular concern to homeless people. As with drug users and some mental health service users, issues of compulsion and behaviour change make it ambiguous as to who is being assisted by services, with consequent implications for user involvement.

2.6.3 Summary

This brief discussion of the recent literature on user involvement has considered the patchy progress made on user involvement across service user groups. The literature reviewed tends to focus, with some exceptions, on problematic barriers to implementation. Good practice guidelines, which have not been reviewed here, tend to highlight the opposite side of the coin: ways in which organisations can facilitate and support user involvement. Robson et al²⁰ take a similar approach, where they note the features of voluntary organisations that assist change through user involvement. They note that involvement was translated into change when there was effective leadership by both service users and profes-

sionals and where the priorities of users took precedence. This study also differs from others in that it was an action research project that considered change over time rather than at a single point.

2.7 Social policy and public sector reform

2.7.1 'Voice and choice'

Beresford and Croft⁷⁴ characterise the current policy context as ambiguous, uncertain, complex and contradictory and recent policy measures reflect this. By way of illustration, an agenda for 'top-down' reform will be discussed.

Recent government policy has emphasised the concepts of 'choice and voice' as mechanisms for public service reform. The intention is that service users will gain more say over how local services are run, by choosing between alternatives and participating in decisions about delivery. The Home Office and other government departments have expended considerable energy encouraging civic participation (for an overview of the issues in relation to the voluntary sector see¹³⁴).

Both choice and voice may be individual and collective. People may choose as individuals (for example, over which person to appoint as a personal assistant when receiving direct payments) and as a group (for example, democratic collective decisions about particular service providers); they may also be involved in user participation (voice) as individuals or collectively.

The Public Administration Select Committee¹³⁵ notes that the government is much more enthusiastic about choice than it is about voice. In their review of evidence, which focuses mainly on education, housing and health but which they state is also applicable to other services, they call for a balanced approach to both strategies. Concern is expressed that emphasis on choice is likely to compromise equity. The greater ability of middle-class service users to choose between alternatives, and move if necessary,¹³⁶ and the likelihood of 'cream-skimming' by the private sector mean that if equity is to be maintained increased and continuing state intervention will be required. While the government has not accepted this argument, it continues to be disputed.

However, within the preference for choice, the preference is for individual choice. Collective choice is seen as a minor strategy that will not

be deployed as a most likely option. The Public Service Reform Team states:

... collective choice means giving groups of users greater power to decide where, when, by whom and how a public service is provided. It is usually best deployed where individual choice is not feasible eg policing, community safety and other local services.¹³⁷

Collective voice (user participation) is discounted by the New Local Government Network¹³⁸ on the basis that it is ineffective and does not deliver speedy results. They further suggest that collective voice may give rise to an unrepresentative elite. Instead, individual consumer voice is suggested as a preferred approach to reform. While naturally these arguments are not uncontested, government statements that downplay voice in favour of individual choice^{137, 139} lead to an equation of voice and individual choice. Voice is barely mentioned in recent statements.

The effect of this is to maintain a clear distinction between service users and service providers and a demotion of engagement as a priority. On the other hand, the issue of effective support for service users to exercise individual choice remains in written policy statements, together with recognition that professional and service providers are not well placed to do this, particularly private sector providers.

Assessment procedures have been consistently documented as problematic for many service users.^{103, 140} Access to services for the kind of help needed is not always easy to secure. Choice is not straightforward because service users do not operate as customers in a free market.

A question for the research is therefore whether user-led services might fulfil the role in the current climate. While not suggesting that this is the only way to instigate and manage change, it may offer possibilities for maintaining collective voice in questions about service provision and could be positioned between service provision and use of services.

2.7.2 Summary

This review has considered the literature from 2003-06 that concerns user involvement and organisational change. As is evident from the preceding discussion, involvement does not lead automatically to change. There is evidence, however, of greater involvement and some steps towards more

of a partnership between service users and service providers. There are now more examples of service users being involved in a wider range of roles and at more organisational levels.

Some instances of cultural change over time have been documented. The literature shows conclusively that this kind of change takes time and effort, and that dismissing involvement as ineffective misses the point. It is evident that it is not a 'quick fix' but a long-term effort.

User-led services are important both for the improvements they offer to service users and for their potential to offer models of good practice more widely. As a form of user participation that can bridge the divide between service users and providers, ensuring adequate funding is likely to require more than a simple increase of 'choice' options based on cost-effectiveness criteria that do not adequately consider the support requirements of service users.

Practice survey methodology

3.1 Introduction

This research is concerned with people – people who use social care services and professionals involved in commissioning and providing services. The literature review revealed a complex picture of interaction between these different groups influenced by varying legislative and social policy backgrounds in the UK and varying impairment groups. Relationships in social care are influenced by many factors including who exercises most power and influence and how service users are organised. There is no particular model or set of rules that can be applied to service user-driven cultural change, therefore an approach of questionnaires with semi-structured questions and focus groups was adopted to allow for a full range of ideas to be considered from which conclusions could be drawn.

3.2 Mapping and questionnaire

The mapping and questionnaire stage of the project aimed to find out about service user-driven culture across as much of England, Wales and Northern Ireland as possible.

The initial project proposal included the aim to send a questionnaire to a wide range of service users and service providers. Discussions with the project advisory committee and SCIE identified difficulties with sending out a single questionnaire to cover service users and service providers.

After looking at various options including sending out two different questionnaires, it was agreed that this would be time consuming and complicated. It was therefore agreed that a questionnaire should be targeted at service user organisations as these would be in the best position to identify what changes had taken place.

The questionnaire (see Appendix C) was designed to identify:

- who was involved and what their role was
- how they are presently involved
- when they became involved
- what contributions service users were making
- what changes service users brought about in the specific area – what changes occurred, what changes were hoped for, changes in progress and changes for the future
- how long the change took
- how change was sustained
- specific examples of policy (such as commissioning services)
- specific examples of practice (such as involvement of service users in training and appointment of staff)
- what good practice in respect of user involvement they considered their organisation could offer
- whether they agreed to participate in a further in-depth practice survey.

The questionnaire was designed to deliver information in terms of the numbers of respondents who saw change having taken place, ratings of whether the process had been difficult or easy, activities and factors that had an impact on the process of change, the future potential for change and threats to progress that was achieved.

Each of the questions then allowed respondents to give information about the issues covered.

The questionnaires were sent out either through email or through the post to 500 organisations across England, Wales and Northern Ireland. These were from selected databases held by NCIL, Shaping Our Lives and People First.

The two project workers analysed the questionnaires to produce figures for the quantitative responses and to code the common issues that came from the responses to the qualitative questions.

3.3 Focus group meetings

The project proposal set out the aims of the focus group meetings as being:

- to investigate more complex issues raised by the research commissioning brief, such as assessing transferability and how to develop sensitive and sound outcome measure to inform resource investment decisions;
- to ensure the involvement of potentially marginalised groups such as BME service users, mental health service users, people with communication support needs etc;
- to involve social service professionals with knowledge and experience in innovation and service improvement based on user-led culture change;
- to seek to identify other external and internal drivers such as funding cycles bureaucracy and monitoring, capacity and provision of services, staffing and training.

The focus groups were identified from the questionnaires with the selection being based on:

- geography – the aim was to do one session in each of the nine English regions, Wales and Northern Ireland;
- evidence of initiating service user-driven change in social care in each area;
- willingness to participate within the timescale set for the research;
- representation across all impairment groups;
- that there was an ethnic mix.

A total of 10 focus group meetings were carried out for the project, with nine in English regions and one in Northern Ireland. It was part of the original plan for one of the groups to be in Wales but there were very few responses to the questionnaire initially from Wales. Disability Wales helped to support the work by sending out additional questionnaires to user-led groups from their own mailing list. The responses received did not indicate that focus group meetings were likely to generate significant additional information, while further contacts did lead to more questionnaires being returned from Wales (with an eventual total of 15).

One of the questionnaires received from Wales in the first batch of questionnaires met the criteria for a focus group in Wales; the organisation concerned was unable to accommodate this due to capacity issues. An alternative user-led organisation was therefore sought from the

returned questionnaires and detailed information over and above that obtained from the main questionnaire for the project in order to cover some of this gap in the information was obtained from an umbrella organisation controlled by disabled people and covering the whole of Wales.

A standard schedule was used for each of the meetings. The focus group facilitators used the schedule to carry out semi-structured interviews with the groups to investigate issues that had been raised in the groups' questionnaire responses.

When arranging the meetings, groups were encouraged to invite a representative from service provider organisations to take part in the meetings. None of the groups were able to do so, although it may have been better that this did not happen, as there were occasions when the presence of a representative from service provider organisations would have inhibited the discussions.

It was seen as important to ensure that the project gave coverage to service providers' views on these issues and to achieve this five telephone interviews were carried out with representatives of service providers in areas where the focus group meetings had shown the most positive examples of change.

3.4 Drawing the information together

The conclusions of the literature review, the findings from the questionnaire and the findings from the focus groups were drawn together in order to reach some conclusions about service user-driven culture change and to reach some recommendations on how change could be brought about more effectively and better sustained.

Practice survey discussion of findings

4.1 Questionnaire

A total of 123 questionnaires were returned.

The questionnaire began by asking whether changes had taken place as a result of user involvement in the past five years. The answer were:

Yes 102

No 19

Two people did not answer this question.

4.1.1 Changes identified

The changes identified break down into the following categories:

New services: 17 respondents – these included developments around direct payments, outreach services and support with issues such as parenting and using public transport.

Maintenance of existing services: one respondent – one organisation had been involved in a campaign to maintain existing services.

Policy change: 17 respondents – change in terms of policy development was clearly a key issue for many respondents. Again there was a broad range of examples including charges for services, quality standards and a charter for older people. These types of policy changes often appear to be achieved by users having places on relevant committees.

Accessible information: two respondents – two respondents described working with service providers on the development of accessible information.

Monitoring and evaluation: five respondents – respondents who were involved in monitoring and evaluation with service providers included one that was monitoring a service level agreement and another monitoring the implementation of a charter for older people.

Staffing issues: 21 respondents – involvement in changes relating to staff and staffing issues was another key area of change. This commonly involved taking part in the recruitment and interviewing of new staff and the training of staff. One group had young people trained to interview staff candidates and fed in their views to the selection panel. Another reported their users had developed materials for use in training and induction of new recruits. In one area the local authority had prioritised the retention of staff after users had stressed the importance of continuity in the provision of social care services.

Education: four respondents – one respondent described being involved in providing training to local authority staff and education staff and the others were involved in social work degree courses.

Development of user involvement: 17 respondents – the development of user involvement itself was a key theme. Respondents looked at this in terms of obtaining funding for more staff, taking on new roles such as providing advocacy support in mental health units, a user participation group, participation in research, users as spokespeople for the organisation and training for users on issues around involvement.

This type of change is important as the development of user involvement clearly has the potential to lead to further change. One respondent's organisation had moved from being an organisation for disabled people to an organisation of disabled people, which was run and controlled by disabled people.

Respondents saw these changes as having led to benefits for service users in terms of more flexible and responsive services that resulted in better quality of life and increased independence for service users. Developments around user involvement were seen as giving service users greater confidence and self-esteem.

Lessons that respondents believed that they had learned from the process of change were:

- change needs to be based on the social model of disability and a community development approach;
- user-controlled organisations need to be resourced if they are to play a role in change;
- resources need to be used effectively;
- service users should be fully involved in change;
- service users need to be involved at a strategic level;
- everyone involved in change needs to be constructive and proactive;
- service users and service user organisations need to be coordinated in their approach to change;
- service users and service providers need to develop positive relationships;
- attention needs to be paid to getting the process right from the start of any changes;
- at a practical level, meetings need to be properly organised and accessible;
- time needs to be allowed for changes to take effect.

4.1.2 Process of change

The questionnaire asked respondents to evaluate the ease or difficulty of change, with the answers being as follows.

Very easy	5
Easy	25
Difficult	46
Very difficult	19

Five people indicated that it varied between the different elements of change. Two people answered that none of these characterisations were appropriate.

Issues identified as making change difficult were:

- power issues, particularly around the inequalities between service users and service providers;
- organisational and staffing issues – this included issues around bureaucracy and the capacity for staff to support the process of change;
- cultural change in an organisation were seen as particularly difficult to achieve because it involves the biggest types of changes;
- funding – this relates to the cost of making change and the possible additional cost of improved services;
- building a consensus about change could be difficult, particularly where there was widespread involvement.

Respondents then gave views on how change could be made easier:

- good practice in user involvement;
- recognition of the social model of disability;
- better understanding of user-controlled organisations;
- funding for user involvement and for the process of change;
- the support of staff and professionals involved in the process of change;
- good relationships between all involved in making change;
- training where required for all involved in change.

Many of these points offer solutions to the difficulties identified in the previous list.

Service users were seen as a key part of the process of change by the vast majority of respondents, with people characterising the role of service users as follows:

Unimportant	0
Important	6
Very important	21
Essential	71

A question about who started the process of change further highlighted the important role of service users, with respondents pointing to the following groups as initiators of change.

Individual users	47
Informal groups	25
Service user organisations	35
Advocacy organisations	19
Representative organisations	7
Professionals	15
Voluntary non-user-led organisations.	12
Local authorities	15
Other (please tell us)	1 – unspecified

Respondents identified the following activities that they/service user organisations had been involved in relation to change:

Consultation meetings	93
Representation on boards, committees	97
Service design	59
Service planning	61
Evaluation	69
Research	57
Information	65
Promotion	51
Lobbying	49
Campaigning	49
Other	2

The ‘Other’ categories added were ‘teaching’ and ‘involvement in recruitment’.

4.1.3 The future

The questionnaire went on to ask whether the process of change and/or progress was continuing, with the answers being as follows.

Yes	78
No	11
Not sure	9
No answer	4

One respondent added ‘very slowly’ and another said ‘yes – with hiccups’.

Examples of continued change included:

- moving from involvement in some staff recruitment to trying to be involved in all;
- renewal of a contract to provide input on the social work degree;
- impetus for further change from monitoring the implementation of a service charter;
- establishing a new crisis house for mental health service users;
- embedding of the social model approach within local social services;
- user involvement taking on a national dimension with the start of the ‘People with Learning Difficulties’ Parliament;
- a move from ‘adversarial approaches’ to working in partnership with service providers.

Two respondents said that they were unsure about whether progress was continuing. Another said that it was but that funding issues were making this difficult.

‘[We are doing] more of the same – continued battling for improvements. Resource factors are making this increasingly difficult.’

People who did not see change/progress as continuing were asked about the reasons for this:

- funding issues
- new priorities taking precedence.

One person felt the change around user involvement had never been a real concern for service providers.

On a more positive note, one organisation said that the process had stopped because all the changes that they had wanted to achieve around user involvement had been reached, although they did say that they were reviewing whether further action might be necessary.

People were then asked whether they had any concerns about progress that they had achieved being lost, with the answers:

Yes	62
No	33
No answer	2

The reasons given for this were:

- funding cuts;
- problems around user involvement – this included issues around the development of good practice in user involvement, particularly with good practice being concentrated with specific staff, which means that it is lost if they move on;
- changes to services – examples included services merging, the involvement of the private sector, changing eligibility criteria and charges for services were seen as negating progress that had been achieved;
- national policies negating local progress/changes.

4.1.4 Where change had not taken place

In drawing up the questionnaire the project team believed it was important not to assume that change would have taken place and they gave respondents an opportunity to look at why this was the case.

Nineteen respondents said that they did not think that change had taken place in the past five years. While the following questions were

intended for the 19 people who had given this answer, some who had answered that change had taken place also completed this section.

Respondents identified the following reason why they believed that change had not taken place:

- poor management ;
- lack of training;
- lack of accountability;
- lack of user involvement;
- lack of resources.

Some respondents felt it was not the case that there had not been any changes but they were critical of how limited they had been:

‘The changes have been cosmetic and the improvements have been bureaucratic.’

Views on what was needed to start the process of change were:

- clearer policies, responsibility and accountability;
- transparent monitoring of services from a consumer perspective;
- better communication between managers and staff;
- better managers.

Three respondents saw the key as proper user involvement, with one saying that change would start:

‘By services genuinely taking on the views of service users and not paying lip service.’

The final question then asked whether respondents thought that change would start:

Yes	9
No	8
Not sure	9

4.1.5 Profile of respondents

The types of service users who worked with by the organisations that responded were as follows:

People with physical impairments	67
People with sensory impairments	59
People with learning difficulties	58
Older people	46
Mental health users/survivors	62
Parents	27
Young people	26
Young people with experience of being looked after/in care	15
Users of drug and alcohol services	13
People with HIV	2
Disabled parents	2

The respondents included organisations working with the following specific target groups:

BME group (not specified)	18
Africans (with HIV)	1
Jewish	1
Latin American	1
Men	17
Women	18
(17 projects ticked both men and women suggesting they did not fully understand the intent of the question. Only one project was a project specifically for women)	
Gay men	4
Lesbians	5
Bisexual	3
Transgender	2

‘No – our group is not targeted at any one of the above groups’ 90

Work and activities of the responding organisations were as follows:

Service commissioning	13
Service delivery	59
Information provision	57
Representation	41
Advocacy	52
User involvement	57
Other	16

Other areas of work identified were:

- self-advocacy
- advice
- training, service evaluation, research
- family decision making
- ‘involves all of the above’
- self-help
- coordinating national friendship network
- campaigning
- education and regulation of social care
- service monitoring
- supported housing
- direct payments support
- all who user our aims
- community support for minority ethnic groups
- education and training of students on social work degree
- service user panel member
- seminar on access
- policy and campaigning, developing capacity of local organisations.

The length of time that responding organisations had existed broke down as follows:

Less than 1 year	4
1-5 years	18
More than 5 years	95

Two organisations noted they had existed for 31 and 37 years respectively, and one said 107 years.

How many service users/members does your organisation represent?

Up to 100	31
100-200	26
200-300	9
300-400	3
400-500	6
Over 500	38

One group had approximately 1,400 members, another referred to representing 2,000 people, and one had 6,000 members. One respondent did not answer this question.

Service users were involved in the management of 110 of the responding organisations; 14 said that users were not involved in the management of their organisations.

Eighty-nine organisations had service users involved in the delivery of services; 23 did not.

4.2 Focus groups

The focus groups were held with:

- the user forum at a parent and children's centre (Eastern);
- a group of people with learning difficulties (West Midlands);
- mental health service users/survivors (group 1) (East Midlands);
- mental health service users/survivors (group 2) (Northern Ireland);
- a group of disabled people (London);

- a user-controlled direct payments support service (South East);
- a group of older people (Yorkshire);
- a service user group who use a range of services (South West).

A total of 55 individuals took part in the focus groups, which were run between September and November 2006.

4.2.1 Changes that had taken place

An impressive range of developments were achieved by the user-led groups included in the focus group work. Ranging from a whole panoply of user-led training and educational work with professionals both in social care and well beyond, to plans and proposals for setting up new user-led services such as post-natal depression groups, a crisis house and CILs. Issues of discrimination in wider society are also actively being tackled by, for example, producing leaflets and videos to combat hate crimes against people with learning difficulties, and groups persuading providers to actively tackle bullying cultures within services. The common theme uniting all these initiatives is that of using and building on service users' real experiences (whether of social care itself or going beyond this), to create meaningful outputs that tackle the real barriers that people face and put in place effective support to service users.

Specific changes described by each group were as follows.

People with learning difficulties group

- General growth in user involvement
- Specific involvement in staff recruitment with social services
- Specific projects on crime and involvement with the police and justice system and on making use of health services easier for people with learning difficulties.

Direct payments support group

- Growth in numbers receiving direct payments
- Growing role of the organisation
- Negative changes around continuing re-organisation of services.

Disabled people's group

- Improvements to domiciliary care services (after some problems resulted from a review)
- Short break care for under-18s
- Negative changes around the closure of services including user-led support for people receiving direct payments and other user-led organisations.

Mental health service user group 1

- Payments for service users taking part in user involvement
- Involvement in research and training, particularly through their local university.

Mental health service user group 2

- Independence for the group that had been a local branch of a national organisation
- Establishing a resource centre as an alternative to the local authority setting up a day centre
- Training for service users to play a more effective role
- Service users providing training to other organisations, including Jobcentre Plus
- General increase in user involvement
- Establishment of user-led groups.

The parents' forum

- The setting up of the centre that the forum represents, which had been done with the full involvement of local parents, and this was seen as a major factor in its success
- Saving a play group that was threatened with closure
- The creation of a post for a parent involvement worker
- Improvements to the toy library service by linking it to the main library service

- Plans to establish a support group for women with post-natal depression
- Training for forum members had helped them to contribute to the work of the centre more effectively.

The group said they had conducted research that showed their work resulted in reduced hospital admissions of the under-5s.

The mixed users group

- The advocacy service had resulted in many changes and improvements for individual service users
- Service users were able to contribute as volunteers
- Participation in user involvement at a regional level
- A handbook for people living in a particular housing association covering issues such as bullying and complaints procedures
- Improvements at a local day centre, including more flexible rules and better food
- More people receiving direct payments.

The older people's group

- Ensuring that concessionary fares were available on public transport
- Work on poverty
- Input into the development of new facilities
- A charter for health and social care with services that set standards that older people could expect from their services
- Individuals being able to live in their own homes rather than move into residential homes.

Information from Wales identified the following key changes had resulted from user involvement or initiatives with significant user involvement:

- strategic developments to support direct payments;
- the development of a unified assessment process that brings together social services, GP and nursing services;

- growing networks of disabled people and service users.

4.2.2 How change had happened

Users from all groups were virtually unanimous in seeing themselves as the instigators of change. Users saw their groups acting as role models for provider organisations, setting the pace and providing inspiration for individual users within these groups to become more involved and raise their expectations. Their success in achieving change came from factors such as their regular internal communication, energy and commitment from user leaders, and the groups giving users significant roles from which they gained confidence and self-respect.

Key issues emerged from three of the groups about how change had been achieved:

- *Leading by example:* the people with learning difficulties group believed that social services' practice of involving service users in staff interviews had developed because of the group's own practice on this issue.
- *The understanding of staff and practitioners:* the direct payments support group saw the growth in numbers of people receiving direct payments resulting from the increased understanding of practitioners; the group described how it could be difficult to get management commitment to new ideas to filter through to frontline service providers.
- *Training:* this was a key issue for the direct payments support service in engaging the support of practitioners for direct payments.
- *Service users as the initiators of change:* the mixed users' group saw it as essential for new developments to come from the perspective and experiences of service users. This was reflected by the mental health service user group 2's view that change came from regular and thorough consultation with service users in the resource centre that it runs:

'It is important to hold meetings regularly so that people are more confident when giving their views – breaking down barriers and boundaries and sharing a two way open relationship – recognising that everyone is human.'

- *Users having significant roles within an organisation so that they began to see themselves as making a tangible and valuable contribution:* in the mental health day centre users' group this happened through service users running/facilitating meetings, running groups within the centre (for example, a drama group) and being a part of the fundraising for the centre.
- *Key individuals:* some people, particularly those in leadership positions, play a central role in supporting the development of change. Again from the mental health day centre user group 2, the manager of the resource centre was seen as having played a key role in the way that the centre had developed.

The common theme through all the groups on this issue is the empowerment and participation of service users matched with the support of staff who were themselves supportive of and receptive to ideas around change. Another key point is that these need to be staff at all levels of an organisation: change will only be achieved where it is supported by managers and frontline practitioners.

4.2.3 Further change

The groups were all asked whether they saw further change as necessary and the view across all the groups was virtually unanimous in saying that further change was needed.

Many were concerned about service providers remaining resistant to many types of change and there was an element of fatalism in some of the groups that further efforts were unlikely to produce further improvements.

‘The attitudinal change needed is massive. We are still dealing with the same issues after 40 years. “They” don’t want to change.’

This said there was some acknowledgement in the mental health day centre user group that the changes that have been achieved were extensive and had exceeded their expectations.

4.2.4 Issues specific to Northern Ireland

The group in Northern Ireland and the organisation in Wales were asked to give details of any specific issues that had affected the way change had taken place in their countries.

The Northern Ireland group suggested that issues around their centre serving a mixed community were not of great significance; subsequent information suggests that there are greater issues now around providing services to migrants from European Union countries.

They also acknowledged that under-funding might be slightly less of a problem for them than in some other areas.

A further point from the group in Northern Ireland was that they generally agreed that general mental health discrimination continues to be very high in Northern Ireland although the group thought that this took second place to sectarian differences, which they saw as continuing to be central to their lives.

4.2.5 Involvement of service users in change

Within user-led organisations, users tend to be meaningfully involved at all levels and all activities: from conception of projects, initiating and guiding, through to actually delivering the work. User-led organisations actively seek to have a voice at local, regional and national levels and to influence both existing services and new initiatives.

Several of the groups interviewed, particularly the direct payments support service, the parents' forum, the mental health day centre users group and the mental health service user group 2 gave examples of how they were able to initiate user-led change.

The parents' forum spoke about being able to respond to changing situations rapidly and also to making economic use of resources, by sometimes withdrawing services they saw as ineffective. They gave the example of having had a problem with the drop-in playgroup run by the centre, as it was becoming over-subscribed and parents had had to be turned away on several occasions. The parents' forum had been able to respond quickly with a decision to implement a rota system, enabling all parents to have some access to the service. They felt this was evidence of their ability to be trusted by funders and statutory authorities to act responsibly.

Similar points were made by the mental health day centre user group who said that user-led philosophy gave rise to most of the changes that had taken place.

The mental health service user group 2 highlighted how they put a strong emphasis on building relationships of trust between professionals and service users:

‘People get to know you, you start to trust them, they start to trust you and it snowballs. Your confidence builds and you feel a lot easier about getting involved. It’s easier to step out of the comfort zone.’

4.2.6 Impact of user-led change on service users

There was overwhelming evidence of the impact of involvement on users, in increasing their confidence and sense of being valued for what they contributed. User-led services were also reported to provide more effective support for users. They experienced a feeling of empowerment and control over their lives that traditional services had not been able to provide. Their relationships with staff in their own organisations were ones of equality and trust and at times their user involvement work also led to an improved relationship with other professionals.

Specific examples of the impact that had resulted from user-led change included the following:

- Having more of a stake in decisions:

‘People now have a voice and will let us know if something is not right – we can then take things forward.’ (older people’s group)

- Feeling more valued and greater confidence as a result of increased involvement:

‘You *are* a human being.’ (mental health day centre user group)

The mental health service user group 2 spoke about how they felt their involvement with the organisation’s resource centre was the first time that they had felt truly empowered.

- Increased take-up of direct payments and greater independence for service users.

These issues point to a number of important outcomes for service users as a result of changes and improvements. As well as the obvious results in terms of better outcomes for individuals and increased quality of life, there are key issues about the increased confidence and self-esteem for service users, and that where this happens there is an additional impact in terms of these service users being better able to play a part in future changes.

4.2.7 Organisational relationships

Relationships between service user and service provider organisations are of key importance but the interviewed groups' relationships with service providers revealed a very mixed picture.

Some groups felt they had robust and meaningful relationships of partnership, whereas other groups had experienced tokenism and being denied the information they needed to participate in processes. Strong progress that had been made could be seriously threatened by structural or policy changes made at national or regional level. Champions could be vital in securing powerful relations with service providers, but are vulnerable to being sidelined or lost in restructuring exercises. On the positive side, contact with outside organisations could sometimes result in unexpected but positive outcomes.

Positive examples included the direct payments support service group where people talked about having a 'genuine partnership' with the local authority. This included being able to challenge the authority where appropriate:

'Although it's an excellent relationship it's not a cosy one. We will criticise them and when we do, we don't pull our punches. They will be fairly robust with us at times too. So it's not a cosy set up but it is a very healthy one.'

In the people with learning difficulties group a support worker said:

‘Social services have asked us to do consultations over the past three years and because people have been involved in a way that has been meaningful, I think that’s changed a few hearts and minds.’

The older people’s group had had mixed experiences but was very clear that having access to ‘the top people’ in the different departments of different services was crucial to the successful work that they had undertaken. There were times when this had been difficult and the group had had to persevere to make the connections. Members of the group did suggest that there are some representatives of services that they trusted more than others.

Negative examples included the disabled people’s group that described a very mixed relationship with the council. Members of the two organisations at the meeting had had opportunities to work with the local authority on the reviews of services but they had clear doubts about the effectiveness of this involvement.

The mental health service users 2 group seems to have experienced some similar problems, describing experiences of tokenistic involvement with examples of patients councils saying that there was no feedback, complaints were not dealt with, and, as a result, nothing was resolved.

However, even with these problems they felt that change was improving the situation and pointed to the importance of having allies among service providers to argue your case when you were not there and noted that changing attitudes and culture was a long slow process.

Organisational relationships are clearly crucial to the achievement of change. The groups’ experiences clearly highlight the importance of relationships that are positive but challenging and can withstand disagreements while taking issues forward constructively. In many this could be characterised as the first level of culture change that needs to be achieved before other issues can be addressed by service users and service providers when working together.

There needs to be recognition that achieving this involves funding for independent user-controlled organisations to fulfil this role.

It is also clear that central government initiatives are having a negative impact on this type of relationship in some areas, particularly changes to the Sure Start programme, where they should be supporting this type of approach.

4.2.8 Relationships with individual workers/managers

Individuals with influence within service provider organisations could make a major contribution to the creation and process of change and sometimes users felt the commitment of such people achieved change even in the absence of any policy framework.

In some cases there were individual staff members who had taken a particular role in the process of change and/or had developed a particular understanding or relationship with the service user organisations involved.

‘Ultimately it’s about getting one person who will understand the principle that we were trying to argue. You get one person at the right level who will listen and things happen.’ (direct payments support service)

Staff turnover could therefore have a significant impact on the process of change. Low rates of staff turnover gave service user organisations the opportunity to build up strong relationships with staff, providing a stronger basis for change. Where there was high staff turnover these relationships would clearly not be so effective and an important part in the process for change would be lost.

There were also clearly issues around differing levels of power between different members of staff, with some staff being in a better position to influence change than others. This could be a complicated issue, as staff in different positions in organisations could influence change and practice in different ways, giving rise to situations where senior management supported change and improvements but they were undermined by lack of support from frontline staff.

One of the groups that had experienced such a situation – the direct payments support service – pointed to the importance of engaging all staff in the process of change and the potential rewards for individual staff members in being part of this process.

4.2.9 Funding issues

Some groups felt relatively secure but there were problems with funding not covering all the activities groups felt they needed to be involved in. Other groups felt insecurity of funding seriously undermined their ability to focus on service delivery.

The groups interviewed included some with relatively secure funding and some that were facing potential problems. Those with more secure funding were clearly in a better position to function and to make a contribution to the process of change.

One of the positive results of this project was to find that so much change had been and could be achieved without funding becoming an overwhelming issue. However, it is impossible to look at any aspect of service user involvement without touching on the issue of funding, as the situation is so precarious for so many groups.

4.2.10 What users need to drive through change

There was a strong consensus among those interviewed about the importance of their own organisations, which provided a non-judgemental, stress-free environment for people to build up their confidence and skills.

This was seen to be essential in enabling service users to move on to influencing outside the organisations and having a role in change. Their own organisations also offered various forms of peer support where people could discover their common experiences, which were an empowering process. Information and regular internal communication were also important.

Other key issues identified were:

- the involvement of service users, with suitable forums and structures to achieve this;
- resources for service user organisations;
- service user organisations to have campaigning/lobbying roles;
- information on all issues that may have a bearing on change in accessible formats so that it was available to all the service users involved;
- the need for professionals to listen to service users and their organisations.

All of these relate back to the need for strong and effective service user organisations that were in a position to drive and support the process of change. These organisations will only exist in a supportive environment that recognises their role and value.

4.2.11 What professionals need to help respond positively to change

The groups interviewed thought that professionals would be helped by being better informed, particularly about the work of service user groups, and by better internal communication within their own organisations.

Interviewees saw a need for consistency between policy directives and staff working at an operational level, and for bureaucracy to be reduced. These issues may be closely linked to the changes of attitude that would lead to greater willingness to listen and to give service users more choice and control – changes that service users regarded as being of crucial importance.

The need to be better informed about service user issues and the work of service user organisations was seen as particularly important and the parents' forum suggested that staff would get a much better understanding of the issues by working more closely user organisations. The disabled people's group also argued that an important part of achieving this was the provision of disability equality training for all staff in service providing organisations.

4.2.12 Poor practice in user involvement

Users continue to encounter examples of poor practice in user involvement and the focus group meetings found examples of this including providers reluctant to move beyond the 'consultation' stage, or even carry out consultation honestly, tokenism and perpetuation of the medical model of disability.

Specific examples of poor practice in user involvement included user involvement being led by staff from service providers and staff leading on the writing of a report because they believed that:

‘They [professionals] control the agenda; our job is to endorse what they consider important things for users. He [a professional] said everything they were doing WAS involvement; I said no, it was just consultation. He said they are exactly the same thing, but I disagreed. I was used to our ways of doing things, I found their way very patronising.’

4.2.13 Making change easier and lessons that could be learnt

For most groups, the capacity and stance of the users groups themselves seemed the most important element in determining the success of change: they referred to the need for users groups getting in a position to be proactive, applying pressure consistently over long periods and ‘being bold’ and insisting on being involved. One group talked about being ‘ahead of the game’ and thinking like a business. At the same time it was impossible to ignore the barriers that stood in the way of change, and groups called for these to be removed: inaccessible meetings, lack of disability equality training within provider organisations, a need for a deeper understanding of the disability movement, social model etc, and a need for greater openness around, for example, mental health issues.

Removing barriers to change was clearly very important. The groups interviewed saw it as particularly important to address issues around bureaucracy and organisational power.

The direct payments support group argued that there was a need for managers in service provider organisations to be more assertive in making change happen in their organisations.

‘Sometimes there is not enough exertion of power. We get an agreement at senior level and they don’t seem to be able to exert enough power of their own staff to make things happen and this causes frustrations, so we would quite like it if the local authority had more internal clout.’

Others came back again to the issue of there being strong and well-supported service user organisations. The feedback from Wales was that the key lesson from their experience of change was to ensure that service users were involved at all levels and in all ways, making a reality of the slogan ‘nothing about us without us’. To achieve this it was important to

establish strong partnerships and networks of service user organisations in order to work together to find solutions, and to do this the capacity of service users needs to be developed through information, training and advocacy and then through support for the development of service user organisations.

Partnership working was also identified as an important issue by other groups but concerns were expressed about how equal the partnerships were between service user and service provider organisations. The mental health service user group expressed particular concerns that these partnerships would always be fragile while service providers controlled the funding of service user organisations and that funding remained vulnerable to cuts.

It was suggested that service user organisations needed to strive to be as effective as possible and to deliver good quality services. The direct payments support group argued that they had been successful by making sure that they took advantage of every opportunity to get involved with different services.

In many ways the most important lessons that were learned were simply that it could be done and that change had been achieved through positive partnerships. The lessons around this again reflect the fundamental importance of developing true and positive partnerships between service users and service providers.

Some groups argued that it was just this type of partnership that best represented what true culture change should look like and what it would achieve. The parents' forum argued that this partnership must be based on mutual respect between service providers and users, and saw a need for some humility on the part of service providers, showing that they valued the process.

They suggested that in practice this should involve:

'A councillor regularly coming to meetings, parents being involved at strategic partnership meetings as equals, actually engaging with parent; accepting that we do know the agenda.'

4.3 Views of professionals

In order to complete the picture of culture change in the areas where focus groups were held, a series of telephone interviews were carried out with

senior social care professionals operating within the same administrative boundaries.

The individuals were selected for their ability to comment on the changes discussed in the focus groups, their willingness to take part, and their seniority enabling them to take an overview of developments over a period of time.

The telephone interviews were based on a pared-down version of the questions used for the focus groups (see Appendix D) and interviewees were given the opportunity to view the questions prior to the interview taking place.

4.3.1 Changes between 2002 and 2007

Professionals described a situation of increasing representation and visibility for service users: users being involved on partnership boards, implementation steering groups for the single assessment process and a mental health alliance consisting of users and professionals engaged in service planning, design and evaluation.

Having users fully involved in meetings at which important decisions are made was increasingly seen as 'normal'.

4.3.2 Involvement of users with the changes

The professionals' view was that successful change results from the convergence of users lobbying for specific changes, and managers and other professionals being open to what users are saying and able to implement the changes.

They highlighted the importance of user organisations being supportive and working collaboratively with service providers. However, in one of the examples given change had been achieved by people with learning difficulties making 'inappropriate' use of a partnership board meeting to raise their concerns about bullying at day centres, indicating that professionals and service providers recognised that there were circumstances in which it was appropriate for service user organisations to be challenging.

4.3.3 Where change has not been enough

There was a clear acknowledgement of the limited nature of change to date:

‘The power has still not properly shifted.’

Interviewees identified the following particular areas where progress had not been sufficient.

Unequal participation: there were areas where involvement and participation was taking place but this was undermined by inequality between service users and service providers/professionals. An example was of a partnership board where users only had limited opportunities to put issues they wanted to discuss on agendas for meetings. The fact that informal discussions take place between professionals outside of meetings also excludes users from many important discussions and issues.

Dysfunctional systems: this refers to situations where issues that should be dealt with in other areas/forums, such as a complaint that should be dealt with through complaints procedures, were brought to strategic involvement forums. The result of this was that neither the complaints nor strategic involvement systems functioned properly. Meetings were used inappropriately by users to raise complaints because they felt they had nowhere else to go with them, and complaints raised via the proper avenues were not being dealt with.

Conflicting agendas: differing policies between central and local government and between different departments in central government were seen as holding back progress. Some professionals feel very constricted by a plethora of targets and regulations, many of which conflicted with each other and with the rightful aspirations of service users to control over their own lives. Examples given included accountability to carers, health and safety, the ‘duty of care’ and fears over the potential impact of the Mental Capacity Act. There was also a particular example of how efforts to include people with learning difficulties in mainstream colleges were being hampered by education policies that encouraged colleges to

offer courses in the community that meant that colleges wanted to offer courses in venues like day centres.

4.3.4 Lessons learnt

Interviewees wanted to see a far more proactive role for professionals in supporting user-driven change, and saw senior managers as having key contributions to make.

It was felt they could help by actively identifying and supporting champions for user-led change at the right level. Support should be given to such champions to enable them to voice users' legitimate demands for involvement in service design, planning and delivery.

There was also a call to investigate the ways in which meetings actually functioned. Many meetings functioned in a tokenistic way, with users present but having no effective way of getting their legitimate concerns on the agenda. Interviewees were clear that ways needed to be found of genuinely engaging with users, whether this was by changing how meetings functioned, or finding other ways to engage with users.

The need to get providers on board was identified: providers who were not engaged at the outset of projects could feel threatened, whereas they may react more positively if they felt some ownership of the change process.

4.3.5 Measurable outcomes

The message from professionals is that outcomes of real user-led culture change could be measured, in terms of real benefits and improvements in quality of life for service users. They wanted to see more attention to these real benefits for users, rather than measuring of paper processes.

There were positive examples of this kind of outcome, such as the use of brokerage schemes enabling people with learning difficulties to do different activities during the day rather than simply attend a day centre. In the case of the user-led mental health day centre, the voluntary attendance rate had increased from less than one third before it became user-led, to full occupancy, suggesting that users were now finding the centre a useful and positive experience.

There were also examples where attention seemed focused on processes, and outcomes were apparently being neglected.

4.3.6 The future

There were different experiences of the continuity of change in different areas with two obstacles to continuing progress:

- commitment to change being concentrated in particular personnel, with the threat that this would be lost if they moved on;
- financial pressures.

At the same time interviews also saw opportunities for user-led change to bring more effective use of existing funds. Doing things better does not necessarily mean making them more expensive, for example, encouraging people to use ordinary mainstream services.

Other threats to future progress were seen as coming from continuing pressures for re-organisations and the pervasive negative attitudes of some professionals, which continue to under-value user-led initiatives and users' own evaluation of what works for them.

An example that combined several of these issues was a health trust that was about to be merged with another, leading to a doubling in size and many changes of roles for personnel. The post held by the 'champion' for user involvement and the emerging culture of 'centre stage' for service users were under threat.

Another concern was that there was too much emphasis on performance indicators that did not address the concerns of service users, although one interviewee thought that this could be addressed through the In Control Programme.

Conclusions

5.1 User involvement as a continuing priority

The theme of user involvement as a continuing policy priority for service providers and a priority for service user organisations is one that comes through strongly in both the research report and the questionnaire and interviews carried out for the project.

The research report identified three approaches to involvement: participation based on Arnstein's ladder model first put forward in 1969; service provision by user-controlled organisations, as exemplified by CILs; and political campaigning.

It found that:

'While the literature consistently discusses the barriers to involvement noted above, most supports user involvement and considers it to be an essential means to service improvement.'

The report goes on to say that current practices limit the effectiveness of user involvement and mean that the pace of change is slow.

The questionnaire and interviews clearly identified user involvement as a key issue for the organisations that participated. Their responses indicated that they seek to have an input into local, regional and national issues in relation to both existing services and new initiatives. Their descriptions of the ways in which they themselves operated as organisations also indicated that they operate according to user involvement principles with their own memberships – with many seeing themselves as role models that service providers had learnt from.

While many obstacles remain to the involvement of service users, there are equally many positive examples. This was reflected in both the research report and in the responses to the questionnaire and interviews carried out by the project. Examples of good practice included full partnership between a local authority and an independent direct

payment support service leading to greater take-up of direct payments, the establishment of a support centre for children and young people, a local charter for health services for older people and a user-led centre for mental health service users/survivors.

The research report looks at the characteristics of user involvement in current reviews and reforms of social policy. It characterises these as being about ‘choice and voice’ – choice about services and having a voice in how they are run. While these can be undertaken individually or collectively, the research report argues that service providers and policy makers prefer to put the emphasis on individual choice.

According to the report, some reports have gone as far as to dismiss collective involvement as ineffective but elsewhere there is recognition that independent support for individuals in making their choices is important and the report suggests that there is a need for further research about this role for service user organisations.

The project report clearly recommends that commissioners and service providers need to be open to the development of user involvement and that professionals need to be better informed through training.

One of the key issues in the early stage of the project was the definitions of change that should be used by the project. This began as a discussion about the scope of the questionnaire survey carried out for the project and the potential difficulties of using a questionnaire that could cover service providers and service user organisations to cover these issues.

Discussions at a steering group meeting indicated that service user organisations would be in a better position to identify where cultural change had taken place, so for this reason, and practical issues around the time resources available to the project, it was decided to concentrate the survey on service user organisations and bring in the perspectives of service providers later in the project.

This suggests that there may be scope for further work on what constitutes change and a more detailed investigation of different perspectives on change and how it is achieved.

5.2 Barriers to participation across different types of service users

Differing priorities and unequal power relationships between service users and professionals were a key barrier identified in the research report. This was seen as impacting on the individual situation of service users, particularly in relation to direct payments, and wider developments and change.

Relationships between organisations and individuals were found to be a key issue in the group interviews and responses to the questionnaire. The professionals interviewed recognised themselves that there is not equity in the participation of service users and that issues such as the cycle of meetings meaning that decisions were taken without involving service users.

Some of the professionals interviewed also questioned the effectiveness of meetings as a way of involving users and suggested this needed to be investigated in order to find ways to improve their effectiveness. They also suggested that alternative methods of involvement might need to be identified.

In areas where there was positive involvement and work for change the interviewees believed they had strong and robust relationships with service providers that could be seen as true partnerships. In other areas the groups felt that they were treated tokenistically and that they were often denied the information that they needed to participate effectively. Some of the professionals interviewed were surprisingly frank in admitting that they did not respond to service users where their views and requests did not fit in with the plans and practices of the service provider.

Organisational relationships are clearly linked to the relationships between the individuals who make up those organisations, and the groups that were interviewed clearly saw these as important in relation to involvement and change. The idea of champions to support involvement and change was seen as important by both service users and professionals. In one area the user group said that the continuation of change was the result of the support of particular staff.

The group interviews carried out for the project found that where individual service users gained considerable benefits from taking part in user involvement in terms of developing confidence and self-esteem,

they also reported that their relationships with other staff/professionals improved as a result of this.

These issues around relationships between service users and the staff of service provider organisations is clearly one that is important for practitioners and for the implementation of user involvement policies. This relationship appears to be the crux point in user involvement particularly in terms of whether it becomes a success or failure and a positive/negative experience for the service users and practitioners involved.

The professionals interviewed for the project explicitly recognised the need for professionals, and senior managers in particular, to be more proactive in supporting user-driven change. They also highlighted the importance of ensuring that the actual providers of services (where there is a division between commissioners and providers) to be engaged in the process.

The issue of the positive/negative experience of this relationship for individual service users is again of great potential importance and may have a significant bearing on practice. Questionnaire responses in particular highlighted the potential individual benefits of taking part in user involvement in terms developing self-esteem and self-confidence. This being the case it might be suggested that user involvement needs to be given much greater priority in one-to-one social care practice.

The point from the professional interviews about service providers not responding to issues raised by service users that do not fit in with their own plans may also need consideration in relation to both individual and organisational practice.

Another issue identified in the interviews and questionnaires that did not appear in the research report was the potential impact of external organisations. This could be positive, as in the example of the media supporting a campaign, or negative, as in some areas where it was felt that central government policies might have a negative impact on local initiatives.

5.3 Differences in experience across different types of service users

It is well documented that there are wide variations in levels of involvement between different types of service users, with groups such as young

people, drug and alcohol service users and users from BME communities often absent from involvement initiatives.

The research report looked at these issues across a wide range of service users:

- children and families
- fostering and adoption service users
- older people
- people with learning difficulties
- mental health systems users and survivors
- people with a sensory impairment
- people with a physical impairment
- service users from black and minority ethnic (BME) communities
- drug and alcohol service users
- homeless people
- carers.

Variations in the influence of different types of service user was not raised as an issue by respondents to the questionnaire or in the group interviews.

Different types of service user being treated differently in relation to user involvement is clearly an issue that needs to be considered at all levels of service provider including individual practice. The extent and nature of the variations may also warrant further investigation.

5.4 Cultural change and resource issues

The research report identified funding and resources as a key issue but did not explore it beyond this. However, it did come out as a crucial issue for the questionnaire respondents and the interviewees.

Several respondents/interviewees saw financial pressures as putting considerable pressure on future developments and continued user involvement, with concerns in some areas that improvements that had been achieved that may have been lost.

This said, in many cases the organisations that took part in the questionnaire and interviews – including the professionals – believed that change and improvements could be achieved within existing resources. Similarly, funding was not the only threat to progress, with organisa-

tional changes such as mergers and re-organisations presenting challenges for some organisations. In one area there was a suggestion that performance indicators are needed to ensure the continuation of and development of user involvement.

Funding and resources would generally be seen as policy rather than practice issues, but given the point above about change that had been achieved within existing resources there may be implications to be considered in relation to practice, particularly at management levels.

5.5 Cultural change as a long-term issue

The research report says that user involvement and participation were seen as the key to change but does not give any details of this.

Responses to the questionnaire and the interviews carried out for the project offer a wealth of examples of ways in which this has happened. These examples include a range of new schemes and services that have been set up as a result of what service users have identified as needed and appropriate.

In many cases, the actual change that had been achieved was around the development and improvement of user involvement, suggesting that involvement may be a key part of achieving change. The interviews with professionals identified the participation of service users in decision making as becoming part of the norm.

This might be an issue that would warrant further investigation and could be seen as relevant to practice at all levels, relating back to the point above about the individual benefits for service users who take part in user involvement.

5.6 Key message

The key message for practice from the project is that cultural change and service user involvement are inherently linked. Improving the practice around user involvement at all levels – which is a cultural change in itself – is the key to improving change in all other aspects of service provision.

Recommendations

Commissioners and service providers

- Be willing to listen and to value the contribution service users do, and can make, to the delivery of better services.
- Ensure senior managers promote service user-driven cultural change.
- Ensure relevant professional bodies provide networking and training opportunities to support service user-driven cultural change.
- Professionals need to become better informed about service users' experience through service user-led training modules as part of regular qualifications to practice in social care.

Decision-making structures

- Service user involvement should be embedded in all levels of decision making that affects the lives of service users.
- The structure for the involvement of service users needs to be agreed with service users at the start of the process.
- Structures for involving service users should be reviewed annually to ensure they are working and are appropriate to the needs of service users.
- Decision-making structures need to be fully accessible not just in terms of providing accessible information but also in terms of understanding and involvement in decision making.
- Decision-making structures should have a specific budget for user involvement.

Support for service user involvement

- Service user organisations should be adequately funded to support service user involvement.

- Such funding should be secure and promote the independence of the service user organisation from local providers.
- Service user-led groups with a record of achievement in user-driven change should be encouraged and given the resources to share their expertise with other organisations through information and training with an annual promotional event sponsored by SCIE.
- Service user organisations need to provide peer support, accessible information, training and skills development in a non-judgemental environment to promote service user-driven cultural change.
- Funding should be freed up to resource user-led organisations to develop their own user-designed services to demonstrate better outcomes for service users and enhanced cost-effectiveness.

National

- Service user-driven cultural change needs national commitment through involvement in national relevant bodies and decision making.
- National policies and strategies must consider the impact on service user-driven cultural change in their development and implementation.
- Performance indicators on user involvement need to include measuring how service users have been involved, how processes have changed to encourage service user participation, and how much support is provided for service user involvement.

Outcomes

- It should be recognised that the central purpose of service user-driven cultural change is to enhance outcomes for service users.
- An annual statement of service user involvement should be drawn up by each provider organisation that highlights what has been the outcome for service users.

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Stop the Drug War: <http://stopthedrugwar.org>
Transform: www.tdpf.org.uk
UK Harm Reduction Alliance: www.ukhra.org/
Values into Action: www.viauk.org/
Welsh Assembly Government: <http://new.wales.gov.uk>

Appendix A

Annotated bibliography

Reference	Notes
Armer (2006) ⁷⁶	A guidance report providing recommendations and advice on user involvement in the Leeds area
Arnstein (1969) ⁶³	An article that outlines a model for understanding citizen participation: citizen power, delegated power, partnership, placation, consultation, informing, therapy and manipulation are described, in descending order of influence. The model is offered as a means of distinguishing between 'the empty ritual of participation and having the real power needed to affect the outcome of the process'
Badham (2004) ⁹⁰	An article that describes the gap between rhetoric and practice with regard to children's rights and participation. Government priorities with regard to engaging children with political processes do not connect with children's priorities, which often relate to use of space on a local level. The article describes the Ask Us! Project, through which young people effected change in one area
Barnes (2004) ¹⁴²	This paper discusses the development of independent living and calls for measures to remove barriers to equality. These include the removal of direct payments from local authority control and giving the administration to service user-led organisations. User-led services as well as cultural change in government departments are discussed as means of effecting the resources needed for disabled people's participation in society

Barnes and Mercer (2006) ⁹	Provides an overview of the development of user-led services as alternatives to traditional services that have been shaped by the preferences of professional providers. User-led services are discussed in the context of the development of the disabled people's movement and the findings from a study into the current situation of user-led services are reported
Barnes et al (2003) ²¹	A literature review on the involvement of disabled people in services and the degree to which this has resulted in organisational change
Beart et al (2004) ¹⁰⁰	Describes how people with learning difficulties benefited from peer support and the process of increasing identification with the group and its aims
Beattie et al (2004) ⁸⁰	A study involving younger people with dementia reporting that people interviewed were well able to express their views. Risk assessment procedures and the provision of age-appropriate services were particular concerns. The authors argue that services need to find ways of consulting such individuals about their experiences
Beresford and Croft (2004) ⁷⁴	'Highlighting four key characteristics in the current policy and political context of social work: <i>ambiguity, uncertainty, complexity</i> and <i>contradiction</i> , this article argues that social work is unlikely to develop a more emancipatory role, unless social work practitioners gain more support to play a central role in its construction and develop much closer links and alliances with service users and their organisations and movements'

Beresford et al (2005) ¹	Report from 13 discussion groups of service users held in various parts of England. Outlines what services users disliked about social care services and what they would want instead
Bewley and McCulloch (2004) ¹⁰²	The report emphasises the importance of peer support to people with learning difficulties in accessing direct payments. There is little independent direct payments support run by and for people with learning difficulties despite this and accessing direct payments remains problematic
Birchall and Simmons (2004) ⁶⁵	This report discusses user participation in public services from a general and theoretical point of view. Different models of participative relationships are suggested and the reasons why people participate are discussed
Breakthrough UK (2005) ¹⁴⁰	A response that emphasises the importance of support for independent living and funding for user-controlled services. Concerns with regard to the intersection of individualised budgets and benefits are explained
Butt (2005) ¹⁰⁹	Factors that serve to exclude and disadvantage black and minority ethnic (BME) people from using services are discussed. Suggestions are made as to how diversity might be promoted and some of the complexities of doing this are pointed out
Canadian HIV/AIDS Legal Network (2005) ¹¹⁶	A manifesto by Canadian drug users calling for the recognition of the human rights of illegal drug users on a national and international level
Care Services Improvement Partnership (2006) ⁷⁵	A report that sets out guidance for expense and other payments for service users taking on involvement work. A broad framework for practice is suggested with details to be worked out at local level

Carr (2004) ⁴	A literature review of research into service user involvement. Problems associated with service resistance are discussed: unequal power relations, resulting in manipulation and marginalisation of some user groups. Service user-controlled organisations are more responsive but face uncertain working contexts. Argues that embedded, continuous but varied participation approaches may be most effective. Concludes with a series of recommendations for practitioners, managers and policy makers about how to set an agenda for organisational change
Cave (2006) ¹¹⁵	The author provides a brief account of supporting user groups of drug users and argues that involvement should not just mean participation in treatment
Chahal and Ullah (2004) ¹¹⁰	A report giving an update on the ways that BME groups experience discrimination with regard to public services. Particular issues highlighted include experience of stereotyping and prejudice, discrimination within their own communities, mono-cultural service provision, lack of information, unmet need and family support issues. Implications for service providers are discussed
Chief Secretary to HM Treasury (2003) ⁸⁷	A Green Paper that resulted from the enquiry into the Victoria Climbié case. The paper emphasises the importance of outcomes for children: being safe, enjoying and achieving, making a positive contribution and economic well-being. Services are expected to work together to achieve these outcomes and the appointment of a children's commissioner is announced. There is a general injunction to involve service users and listen to their views

Clare and Cox (2003) ⁹⁶	Argues for a more purposeful approach to involving people who have cognitive and communication impairments
Clarke and Statham (2005) ⁹⁵	This article provides an overview of recent initiatives to include the voice of children in services and suggests ways of ensuring that younger children are listened to
Coleman with Rowe (2005) ⁹¹	This report considers young people's engagement with citizenship and democracy in terms of internet use. It argues that political institutions are disconnected from young people and that political activity should be planned with the needs of young people in mind. Young people need more support to find information and targeted information from trusted sources or youth-created content is preferable
Crawford et al (2003) ⁷⁷	A literature review that discusses organisational change and service user involvement in the NHS, social services, voluntary and private sectors. Concludes that there is not much evidence of change having taken place, especially in instances where re-allocation of resources was required
CSCI (2004) ⁶⁹	A report that discusses direct payments and examines reasons why the take-up has not been higher. Recommendations are offered for national and local government and concerned organisations
Cutler (2003) ⁸⁶	Suggests a straightforward approach for setting standards concerning young people's participation in services. Reviews the performance of a variety of different approaches to setting standards

<p>Danso et al (2003)⁹²</p>	<p>A literature review on the extent to which children and young people’s involvement has brought about change in public services. Reports on the fact that participation is still limited by barriers and that marginalised children are less likely to be involved. While some limited evidence of service change is reported, the emphasis has been on process rather than outcomes</p>
<p>Dearden-Phillips and Fountain (2005)¹⁰¹</p>	<p>Gives an account of the setting up and workings of the ‘parliament’ model, whereby people with learning difficulties meet together as representatives of a wider constituency. Some specific changes that took place as a result are mentioned, and wider cultural changes outlined</p>
<p>DfES (2004)¹²³</p>	<p>Outline of the duties of independent reviewing officers concerned with the welfare of looked-after children. Arrangements for ensuring the participation and support of children in meetings concerned with them are explained</p>
<p>DH (2005)¹⁰³</p>	<p>This guidance sets out rights to assessment and information about direct payments to children and carers</p>
<p>DH (2006)¹⁰⁴</p>	<p>A White Paper that outlines changes in a range of service provision, including bringing together health and social care services and expanding personalised funding</p>

Emerson et al (2005) ⁹⁷	A report considering whether person-centred planning was effective in improving outcomes for people with learning difficulties. Progress of 25 people in four geographical areas was followed. Labels of mental health or emotional/behavioural problems, autism and mobility impairment meant it was less likely a plan would be received. Those with a plan gained access to more community activities but were not more socially included. The report concludes that person-centred planning is helpful but not sufficient
European Association for the Treatment of Addiction (2004) ¹¹⁷	This report records service users' views on drug treatment services. Recommendations for a large number of changes are made, based on feedback received. The agency notes that opportunities to influence the direction and development of services through direct involvement in policy are almost negligible
Fyson and Ward (2004) ⁹⁹	Based on the findings of a two-and-a-half year research programme, this report offers practical examples of good practice in implementing strategic change in services to people with learning difficulties. It follows on from the <i>Valuing People</i> White Paper, and makes suggestions about person-centred planning, employment and day services, housing and user involvement

Gabriel and Bowling (2004) ¹³⁰	A report of a national survey of quality of life based on 999 older people over the age of 65 living in private households in Britain. Important issues reported were having good social relationships, help and support, living in neighbourhoods that give pleasure, that feel neighbourly with access to facilities including transport, having health and mobility, enough money to meet basic needs and to enjoy life and have independence and control over one's life
Graham-Jones et al (2005) ¹³³	The article reports on a study that compared self-reported health outcomes of homeless people who were allocated a health advocate in comparison with those who received health services without an advocate. Concludes that advocacy is effective in improving outcomes experienced
Hasler (2003) ⁶⁴	A report of research into user participation at higher organisational levels. Users had full roles, as board members, chairs etc, but the range of participation was not broad. Considers a number of issues: organisations have not changed as a result, the numbers on the board matter, governance (top-down) is at odds with the user movement (bottom-up) and there is the possibility of co-option. May not be the most effective way for users to influence services

Hasler and Stewart (2005) ²⁶	A report into the situation in two government areas: Yorkshire and Humberside and the North East. Direct payments worked best in local authorities where a supportive local authority infrastructure combined with both an understanding of the principles of independent living and a commitment to partnership with users. Where direct payments have been most successfully developed, local authorities fund user-led support organisations
Hewitt (2006) ¹³⁹	A speech by the health minister that makes a case for competition and contestability in health service reforms. It is maintained that a new organisational form will characterise NHS trusts, with control exercised by local communities
Hill et al (2004) ⁸⁹	An overview of issues relating to the participation of children and young people, including a discussion of the conflicts between policies that are punitive and those that seek to increase involvement. The importance of use of space, being listened to and fairness is raised, and questions of democracy and representation. Concludes with a series of recommendations
Hodge (2005) ⁷³	The article discusses the ways that existing institutionally defined power relations were maintained in a forum involving mental health service users and service providers

House of Commons Public Administration Select Committee (2005) ¹³⁵	A report that considers issues of choice in service provision, and influence (voice) in service design. Health, housing and education are particular concerns. The report recommends a stronger government commitment to increasing the voice of service users and discusses the complexities of increasing choice. Choice between service providers is distinguished from 'choice from variety', where service users are offered different services by one provider
Hudson (2006) ⁸⁸	Argues in favour of a 'person-centred' approach to organisational change as opposed to 'top-down' policies
Hudson et al (2004) ²	A report into service user views about social care services. The outcomes identified as desirable by service users are contrasted with policy priorities. It is argued that changes need to be made to bring services into line with users' priorities
Janzen and Law (2003) ¹²⁹	Literature review commissioned by SCIE for a broader review. Provides details about research into the involvement of older people and concludes that despite some instances of good practice, there is almost no evidence of user involvement leading to change in service provision in line with the established wishes of service users
Jochum et al (2005) ¹³⁴	An overview of government priorities for encouraging active citizenship and a comparison with the priorities of the voluntary sector. The argument is presented that while government priorities have focused on renewing people's involvement with political processes, many people are more concerned with issues rather than process

Jolly with Priestley (2004) ⁷⁰	A working paper that presents data on the spread of direct payments across the UK. The different take-up rates between local authority areas and between service user groups are discussed
Joseph Rowntree Foundation (2004) ³	Report of the Older People's Steering Group. Highlights the difficulties of unresponsive services, especially with regard to older people's life experiences and social connections. Notes there are few good examples of user involvement and calls for standards on: numbers of older people involved, the stage at which they are included, ability to influence outcomes, resources and involvement throughout the whole process
Joseph Rowntree Foundation (2005) ⁶⁷	In their response to the Green Paper, the Foundation also gives a summary of findings across research reports. The importance of user involvement and funding for user-led services as well as person-centred approaches to planning for people with learning difficulties is emphasised
Langan and Lindow (2004) ⁸¹	The authors argue that 'the continued focus upon risk in mental health services means that there is a danger that people so defined will be excluded from decision-making about their lives. Defensive practice is also more likely'. Seventeen mental health service users, 10 relatives, 6 friends and 56 professionals were interviewed over two time periods. Practice was variable and depended on the initiative of individuals
<i>LDAN News</i> (2006) ¹²¹	A special edition of a newsletter containing articles, news and commentary on the involvement of drug and alcohol users

Macgregor and Hill (2003) ¹⁰⁵	A report of a study about carers' access to assessment. Only a small increase (from 21% in 1997 to 32%) was reported. Many did not know about their rights to an assessment. Where carers received an assessment, 37% experienced an increase in services, which was more likely to focus on health issues rather than breaks. Direct payments offered a positive alternative to the problems of social care staff
Mayor of London/Greater London Drug and Alcohol Alliance (2005) ¹²²	The report described initiatives to involve service users in three geographical areas in London. Using Arnstein's model of a ladder of participation, suggestions about appropriate strategies are provided. The report describes successful outcomes from 'real time community change', whereby service users were given funding to set up projects
Morgan (2005) ¹²⁴	A survey setting out the views of fostered children and foster carers. Issues included not having enough information (for both parties), children's knowledge about care plans, contact with birth families and getting foster placements right. Foster carers were concerned about lack of support from social services and financial hardship. Fifty per cent of children said their views were asked for in the family and that this made a difference, 25% said it made some difference and 15% said they were not listened to or their views made no difference
Morgan (2005) ¹²⁵	A report presenting findings from inspections of children's services. The majority of services passed the standard for involvement of children, with smaller numbers receiving a commendation or unsatisfactory grade

National Treatment Centre for Drug Abuse (2004) ¹²⁰	Provides examples of groups of users and carers who have influenced some developments in local services
NCIL (2006) ⁸⁴	This response to the Green Paper draws attention to the under-resourcing of Centres for Independent Living (CILs) and other user-led organisations. Issues highlighted also include adequate assistance, self-assessment, charging for services and the need for training
New Local Government Network (2003) ¹³⁸	The concept of choice is discussed in terms of the way that it might influence the development of local services. Collective user involvement (voice) is briefly discounted as an effective mechanism for change. Individual voice is offered as a preferred strategy
Newbigging and Lowe (2004) ⁸²	A report discussing the limited implementation of direct payments in mental health services in several localities. Issues include the need for specific support and advocacy, for culture change in services, and for information about payments. Additional problems concern the split between health and social care services
Oldfield and Fowler (2004) ⁸⁵	A wide range of statutory and voluntary organisations were surveyed and responses received from those working in organisations. Young people were not consulted. Reports on subjective judgements of organisational personnel
O'Mara (2005) ¹¹⁸	Statement arguing in favour of the involvement of active drug users on the basis of the immediacy of their experience

<p>Patel (2005)¹¹¹</p>	<p>Service unresponsiveness to the needs of refugees and asylum seekers is discussed, together with an analysis of their disadvantaged position. It is suggested that a more imaginative and proactive approach to finding out what people need and to user involvement is necessary</p>
<p>Pearson (2004)⁷¹</p>	<p>This paper provides an outline of policy developments in direct payments provision across different parts of the UK and between service user groups</p>
<p>Phillips (2004)¹³²</p>	<p>Guidelines on how to involve homeless people in services. Acknowledges that in comparison with other service sectors, homeless people have yet to be involved to any great extent, and that non-traditional forms of involvement may need to be adopted</p>
<p>Postle et al (2005)¹³¹</p>	<p>Advocates a role for professionals in countering the political exclusion faced by older people. It is argued that in turn this action may positively impact on ageist discrimination in healthcare and other services as well as counter broader exclusionary processes in society. The study reports on findings from focus group discussions with older people</p>
<p>Public Sector Reform Team (2006)¹³⁷</p>	<p>This discussion paper outlines the government's approach to public service reform. The model comprises top-down performance management, users shaping the service from below, market incentives to increase efficiency and quality of service and capability and capacity. Choice is prioritised over voice</p>

Robson et al (2003) ²⁰	A report from an action research project involving 11 projects. Change was driven by leadership of both managers and users. Key enablers were 'consistent commitment to user-centred user involvement, translated into practical change at many levels'; and supportive leaders (both user and management) who facilitated opportunities for users to have influence. Change occurred where users' priorities took precedent. Barriers and features indicating success are discussed
Rose (2003) ⁸³	'Service users tend to be unaware of the major way in which their care is co-ordinated but even less involved in it. On the rare occasions service users are involved in their care and other elements of empowerment are in place, they are more satisfied overall with the services they receive.... Increasing co-ordination of care at a managerial level does not necessarily lead to greater awareness or involvement amongst individual users of CPA. This may be linked to the way service workers are perceived by their mental health workers and it is argued this needs to change if users are to be full "partners"'
Rose et al (2004) ⁷⁹	A literature review that examines the relationship between mental health service user involvement and organisational change. Key issues identified include the important role of process in user involvement, the difficulty of measuring changes and different views on what constitute successful outcomes. Changing organisational culture is seen as crucial for the success of user involvement

Roulstone et al (2006) ²³	A report on carer involvement in the UK. The position paper concludes that although many local authorities and primary care trusts are trying to involve carers, and many provide feedback on what is happening, there are structural problems that inhibit the effectiveness of organisational change. Evidence of organisational change as a result of carer involvement is limited
Rummary (2006) ⁶⁸	The author argues that while some benefits may ensue from partnership working between health and social services organisations, changes are unlikely to take place unless it serves the purpose of service providers and service users are involved from the outset. Evidence suggests that partnership working may divert resources away from meeting service user needs
Secretary of State for Health (2005) ⁹⁸	A report on the progress of <i>Valuing People</i> (2001). The report asserts that people with learning difficulties should have a say in making decisions and that services should listen to them. Key areas discussed are advocacy, direct payments and individual budgets, person-centred planning, communication and family carer networks. The report notes continued exclusion of minority ethnic service users
Shaping Our Lives National User Network (2003) ¹¹³	The report details the Shaping Our Lives project with four local organisations of service users: Black User Group (West London), Ethnic Disabled Group Emerged (Manchester), Footprints and Waltham Forest Black Mental Health Service User Group (North London) and Service Users' Action Forum (Wakefield). Discusses user involvement and service evaluation and how these are combined into a focus on outcomes. Particular focus on 'race' and ethnicity

Shiner et al (2004) ¹¹⁹	The report argues that difficulties and risks associated with community involvement were largely resolved by professionals through an emphasis on partnership and retention of power. There was little evidence of drug user or carer involvement in strategic decision-making structures. Welfare-based strategies rather than law enforcement are suggested as a way forward, as communities generally perceived law enforcement to be the responsibility of the state
Sinclair (2004) ⁹⁴	An article that provides an overview of issues relating to the involvement of children and young people, including a review of recent literature on participation
Singh (2003) ¹¹⁴	Discusses the varied experiences of four minority ethnic organisations of disabled people and points to the importance of acknowledgement of cultural background and life experiences as a way of making links. Making space for the discussion of personal experience was effective in bringing about change, increased awareness of rights and abilities to use experiences when training service providers
Stuart (2005) ¹¹²	Reviews issues concerning the low take-up of direct payments among BME service users and puts forward reasons why they will not be fully embraced as well as reasons why they are not easily available. Suggestions are put forward as to how direct payments might be made an effective form of support
Swain and Walker (2003) ¹⁰⁷	Discusses the findings of a small-scale study into relationships between parents and professionals. The question of power relationships between the parties is examined

Tisdall and Davis (2004) ¹⁴¹	Using the UK literature on policy networks, a participatory project is examined in terms of its ability to achieve certain objectives
Thomas (2005) ¹²⁶	A study about care managers' attitudes to looked-after children's participation. The author concludes that there is evidence of some change, particularly in children's formal representation; their participation in actions taken with regard to their own care was less marked. The suggestion is that this change has come about as a result of the according of formal rights through national policies
Thorlby (2006) ¹³⁶	A report that considers HIV patients' ability to move between hospitals. While it was possible to create services around the needs of patients, the fact that not all elected to move opened up the possibility of increasing inequality. Those that moved were more articulate and could complain more loudly. Concludes that the challenge is to make sure that vocal patients are able to improve the services that are poorer
Tobin and Vick (2004) ⁷²	A review of direct payments policies written by local authorities. While most included statements about user involvement and independent living, some material was out of date and did not reflect more recent guidance. The effect of this was to restrict access to some user groups, particularly older people. Most policies referred to user involvement in financial monitoring but not to involvement in the strategic working of the schemes themselves

Turner and Beresford (2005) ²⁴	This report describes difficulties faced by disabled people who take part in user involvement. While many may be paid for their time, benefit system rules and unhelpful attitudes from Jobcentre Plus staff may penalise participants unfairly. Changes to benefit rules, particularly with regard to permitted work and means-tested benefits are recommended, together with training for Jobcentre Plus staff
Turner et al (2003) ²²	Report on two local service user consultation events in Shropshire and Sheffield. Views on benefits, social care services, mental health and public safety and mental health are reported. Those consulted reported scepticism regarding user involvement and care services on a number of levels, including outcomes from involvement, expectations and the organisation of services
Voice for the Child in Care (2004) ¹²⁷	A report on the views of children in care about living in children's homes, being fostered, social workers, education, relationships, making decisions, leaving care and identity and image. Recommendations about service improvements based on children's views are provided
Wallcraft and Bryant (2003) ⁷⁸	A report that provides details about mental health service user groups in England. Argues in favour of increased resources for user groups and for increased influence for groups at a national level
Watson (2006) ¹⁰⁶	This report argues that carers' rights are being ignored because they are not receiving the assistance they should. Rights to life, freedom from inhuman and degrading treatment, to family life, and to education are not adequately considered

Wilson and Evets (2006) ¹²⁸	This article argues that foster care is becoming increasingly professionalised. This may be a means by which managers may exert control over the workforce
Wright et al (2006) ⁹³	Provides a guide to involving children and young people from the perspective of social care organisations. The emphasis is on the process of involvement in design, delivery and review of services
Young et al (2006) ¹⁰⁸	Concerns decision making regarding physiotherapy services for children with cerebral palsy. Practitioners had most power to implement decisions, and parents had more than children. Most decisions were taken unilaterally
Young (2006) ⁶⁶	This article synthesises three studies seeking to evaluate partnership working across health and social care services. Issues discussed include balancing the voices of different groups, the relative success of some groups (mental health service users, people with learning difficulties and older people) in comparison with others (drug users, children). Further issues were the preference to ask users to comment on existing decisions rather than those to be made, and the length of time needed for successful collaboration to develop

Cross-referenced index

Publications concerned with the perspectives of particular groups regarding involvement in services are listed here to provide a cross-reference for the publications cited above. More studies now discuss service user involvement across user groups and where this is the case, the sources are listed in the row 'Across all user groups'.

Within each of the categories there are still areas of overlap. For example, literature on carers, families and children and fostering and adoption shares similar concerns. This is also the case for people who are homeless or drug/alcohol service users. Finally, people with physical and sensory impairments have been placed in the same category here because there is not a strong distinction in the literature.

Category	Numbered reference(s)
Children and families	85-87, 89-95, 107, 108, 141
Fostering and adoption services	123-128
Older people	3, 129-131
People with learning difficulties	96-102
Mental health service users	73, 77-83
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Drug and alcohol service users	115-122
Homeless people	132, 133
Carers	23, 103-106
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Appendix B

Steering group

Shaping Our Lives, the National Centre for Independent Living (NCIL) and Leeds University Centre for Disabilities Study would like to thank the commitment of the Steering Group that met at the offices of NCIL to offer a steer on the project. They included the following individuals and organisations:

Colin Barnes	Centre for Disability Studies, University of Leeds
Don Brand	Social Care Institute for Excellence
Patricia Chambers	Shaping Our Lives, Hammersmith and Fulham Black User Group (Bugs) coordinator
Vicki Holland	Local authority in North Wales (on secondment)
Sara Lewis	Social Care Institute for Excellence
Laura Luckhurst	NCIL, research consultant
Sandy Marshall	NCIL, contracts manager
Liz Ranger	Contact a Family
Simon Stockton	Association of Directors of Social Services
Dean Thomas	Disabled Parents Network
Michael Turner	Shaping Our Lives, research consultant
Miranda Evans	Disability Wales

Appendix C

Questionnaire

Service user-driven culture change

1. Contact details

Name of organisation: _____

Address of organisation: _____

Postcode: _____

Telephone number: _____

Fax number: _____

Email: _____

Contact person _____

Would you like to receive an email summary of the research findings?

Yes (please tick)

2. Details of your organisations

a) Which are the main service user groups served by the organisations? (please tick one or more boxes that apply)

People with sensory impairments

People with learning difficulties

Older people

Mental health users/survivors

Parents

Young people

Young people with experience of being looked after/in care

Users of drug/alcohol services

b) Is your group specifically targeted at one or more of the following? (please tick one or more boxes that apply)

Black or minority ethnic group

Please specify which group _____

Men

Women

Gay men

Lesbian

Bisexual

Transgender

No – our group is not targeted at any one of the above groups

c) Is your organisation primarily concerned with any of the following? (please tick the box that applies)

Service commissioning

Service delivery

Information provision

Representation

Advocacy

User involvement

Other – please tell us _____

d) How long has your organisation existed?

Less than 1 year

1-5 years

More than 5 years

e) How many service users/members does your organisation represent?

Up to 100

100-200

200-300

300-400

400-500

Over 500

f) Are service users involved in the management of your organisation?

Yes No

g) Are service users involved in the delivery of services?

Yes No

h) If you have answered yes to (f) or (g) please say how service users are involved

3. Details of changes that have taken place

Important – Sections 3-5: these questions are for organisations that believe change has taken place as a result of user involvement.

a) Have changes taken place as a result of user involvement within the past five years? (please tick boxes that apply)

Yes Please go to question (b)

No Please go to Section 6

b) Can you give us any specific examples of the changes that have taken place in terms of policy and practice? Examples might include service users being involved in commissioning services or in the appointment and/or training of staff.

c) What difference do you think this has made to service users' lives and the services people receive?

d) What lessons could your experience of user-led culture change offer to other organisations?

4. How change has been achieved

a) Overall, would you say that achieving change was (please tick the box that applies)

- Very easy
- Easy
- Difficult
- Very difficult

b) Can you explain why?

c) What would have made it easier to achieve change, or what would make it easier to achieve change in the future?

5. The people involved

a) How would you describe the contribution of service users to the process of change identified above?

- Unimportant
- Important
- Very important
- Essential

b) Who started the process of change?

- Individual users
- Informal groups
- Service user organisations
- Advocacy organisations
- Representative organisations
- Professionals
- Voluntary non-user-led organisations
- Local authorities
- Others (please tell us) _____

**c) How and in what ways have service users been involved?
(please tick one or more of the boxes that apply)**

- Consultation meetings
- Representation on boards, committees
- Service design
- Service planning
- Evaluation
- Research
- Information
- Promotion
- Lobbying
- Campaigning
- Other (please tell us) _____

d) Has there been any evaluation of the changes that have taken place?

Yes

No

Please could you send us any evaluation reports you may have.

6. Where change has not taken place

Important – Section 6 is for organisations who do not think that change has taken place.

a) Can you say why you do not believe there have been any changes or improvements in social care?

b) How do you think it would be possible to begin a process of change?

c) Do you believe that change will start to happen?

Yes No

7. The future

a) Is the change or progress continuing?

Yes No

If yes please can you tell us what is happening now?

If no, please can you tell us why you think it has stopped?

b) Do you have any concerns about progress that you have achieved being lost?

Yes No

If yes please can you tell us about what is happening and why you think improvements that you have achieved are being lost.

8. Participation

When we have received completed questionnaires we will be selecting some areas to visit to interview people who have been involved in these changes. We are able to pay service users a fee and pay for their support costs in order for them to be involved with this project.

Please tick here if you think you or your organisation would like to participate in some further interviews.

Yes No

9. Data protection

The information that your organisation supplies will be used to create a **knowledge review** on behalf of the Social Care Institute for Excellence that will be made available to the wider social care sector.

Please therefore sign and date the completed form to indicate your organisation is happy for us to use the information supplied.

Signed by/on behalf of _____

Date _____

Appendix D

Questionnaire used for telephone interviews with professionals

Changes that have taken place in the past five years

Can you briefly describe key local changes in social care that have taken place in the past five years?

What has the role of service users been in these changes?

Learning/transferability

What lessons could other organisations learn from this process?

Are there ways that outcomes can be measured from the changes that have occurred?

Making it stick

Is the process of change continuing? If so, how?

Are the positive changes that have taken place secure? Are there any threats to the progress that has been achieved?

End March 2007

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Developing social care: service users driving culture change

This knowledge review sees the National Centre for Independent Living (NCIL), Shaping Our Lives and the University of Leeds looking at service user-driven culture change.

The knowledge review looks at current literature and practice around service user involvement, the extent to which service user involvement has brought improvements to social work and social care and where the change has become established practice.

**This publication is available in an
alternative format upon request.**

Social Care
Institute for Excellence
Goldings House
2 Hay's Lane
London SE1 2HB

tel 020 7089 6840
fax 020 7089 6841
textphone 020 7089 6893
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