

Seldom heard: Developing inclusive participation in social care



Seldom heard: Developing inclusive participation in social care

Paul Robson, Alice Sampson, Nnamdi Dime, Louisa Hernandez and Rachael Litherland,
Centre for Institutional Studies, University of East London

First published in Great Britain in September 2008
by the Social Care Institute for Excellence

© SCIE 2008
All rights reserved

Written by Paul Robson, Alice Sampson, Nnamdi Dime, Louisa Hernandez and Rachael Litherland

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

Front cover photograph kindly supplied by Janine Wiedel/Photofusion.

Acknowledgements	iv
Summary	v
Introduction	1
Scope of the report	1
Research method	1
Background issues	2
Policy context	2
Who are 'seldom-heard' service users?	3
What is meant by 'participation'?	4
Case study research findings	5
Getting involved	5
Models of participation	6
'Everyday' participation	6
Inclusion	8
Practicalities of participation	9
Working with uncertainty	11
Changing role of professionals	12
Protected spaces	12
A model for everyday participation	15
Conclusion	18
References	19
Further reading	22

Acknowledgements

We would like to thank:

- all staff and members of Islington Age Concern Sotheby Mews Centre, especially the staff and participants from Alsen Day Centre (members of the Greek group), Caribbean Pensioners and Friends and Asian elders group Sotheby Mews Centre, who contributed to the research
- staff and young people from Impact Initiatives Young Peoples Centre, especially the staff and young people who took part in the interviews and shared their experiences
- people who use services, members, volunteers and staff from Aldgate Hostel, London; St Anne's Centre, Leeds; West Kent Alzheimer's Society; Elm Centre, Glasgow; Kent Sensory Disability service; Connect national office; and Access to Life project, Cornwall.

We would also like to thank the members of the users' reference group who gave invaluable advice on the research, the findings and the issues of participation for seldom-heard groups.

Summary

This position paper provides a practice framework to help practitioners and managers of social care services enable the inclusive, everyday participation of people from 'seldom-heard' groups.

The study focuses on four groups: homeless people with addiction problems, people from black and minority ethnic communities, people with communication impairments and people with dementia. SCIE has identified these people as less likely to be heard by practitioners, managers and decision makers because of the way that services and institutions operate.

Debates about participation have tended to talk about 'hard to reach' people, suggesting that there is something about these individuals that prevents their engagement with services. 'Seldom heard' is a relatively new term, which stresses the responsibility of agencies to reach out to excluded people, ensuring that they have access to social care services and that their voices can be heard.

The proposed framework is based on findings from previous research, a brief literature search and primary case study research. The visual model (see Figure 1) was developed to show how, through confidence building and organisational support, practitioners and people who use services can work together to move from participation as an add-on to participation as an integrated, everyday way of working. The practice framework and the model are offered as a starting point for others to test and develop.

Participation

The services and projects taking part in this study operated within different policy and funding environments, and approached participation in different ways. Research identified two polarised approaches to participation. The first approach viewed participation as a discrete activity which organisations and staff attempted to plan and carry out in addition to delivering services. The second approach made no distinction between service delivery and participation: participation was part of everyday activities and relationships.

Values

Efforts of staff to build strong relationships with people who use services, developing trust, mutual understanding and respect, provided a value base for an integrated approach to participation. Staff did not make assumptions about why or how an individual could be involved. People who use services were at the centre of the process. Interviews with people who use services highlighted the importance they placed on staff who acted in ways that were inclusive and non-judgemental, and who were positive about the potential of people who use services.

Practicalities

People who use services and staff recognised the need for effective practical arrangements, ensuring access to information, services and debates. Service users wanted to know what was expected of them, what they could expect from participation in a service or event, and what feedback they would receive about the outcomes. This way of working became second nature for staff committed to an everyday approach to participation.

Tensions

The experiences of staff and service users in the case studies revealed a number of tensions which hindered an everyday approach to participation. For example, people using services appreciated flexible arrangements but also wanted clear messages about why they were being asked to take part. Resolving such tensions required staff and people using services to negotiate how they work together. For staff this meant a shift in professional roles from being seen as the expert to recognising the expertise of people using services and sharing decision making. A table showing a range of tensions is included in the report.

Barriers

The research revealed a number of barriers – attitudinal, organisational, cultural and practical – to achieving everyday involvement of people from seldom-heard groups. A tick-box approach to user involvement, the demands of programme monitoring or funding conditions and unsupportive organisational environments were cited as barriers. Key enabling factors identified by many staff and people who use services included time and money, suggesting that time-limited activities will always have limited scope for engaging seldom-heard groups. The report offers some good practice ideas for overcoming barriers.

The practice framework

Based on the case study research, especially the experiences of people who use services, a practice framework for everyday participation was developed. The visual model presented in the report shows how the practice framework can become a practical reality. It summarises essential elements that will enable practitioners to help people using services from seldom-heard groups engage with services and projects in ways that are suited to them and lead to positive outcomes.

Moving on

Everyone has the right to be involved in planning and making decisions about their everyday lives and the services they receive. The voices of some people, however, are less likely to be heard. This report suggests that seldom-heard users of social care services can become engaged if practitioners and managers adopt an inclusive approach to participation.

The report describes the value base and characteristics of everyday participation, the organisational tensions and barriers that hinder best practice and practical action to overcome barriers. The proposed practice framework, summarised in the practice model, can help practitioners and managers move from participation as an add-on to an integrated, everyday way of working.

Introduction

Ensuring that the voices of seldom-heard service users are not marginalised is a key challenge for practitioners and managers. It is crucial that people from seldom-heard groups are able to take up the opportunities presented by the personalisation of social care services. This position paper offers a practice framework to help practitioners and managers of social care services whose role includes enabling the participation of people from seldom-heard groups. The framework is derived from key findings identified in previous research, and from primary case study research examining the processes of participation for four groups of people who use services identified by SCIE as 'seldom heard': homeless people with addiction problems, people from black and minority ethnic communities, people with communication impairments and people with dementia.

Scope of the report

The report focuses on people who were engaged with services and had experience of participation to draw on, so we could build a model. The practice framework will be most relevant to practitioners and managers who work within service provider organisations. It aims to support the positive engagement and participation of seldom-heard service users from the point at which they first made contact with a service.

The research and practice framework do not cover the issues of finding or accessing members of seldom-heard groups. This is an important separate issue which was beyond the scope of this project. In our literature search we did find some useful ideas about access to services and consultations, for example by positive targeting of seldom-heard groups (Ahmed et al, undated; CCNAP, 2001; Warburton, 2006). We have also used information from this literature search to inform how we developed the practice model.

We offer a practice model which summarises our research findings as a starting point for others to test and develop the ideas. The model is derived from a small number of cases and therefore the extent to which it applies to other settings and service user groups needs to be tested.

Research method

The aim of the research was to identify the models used by people who use services and practitioners by asking them about how the processes of engagement and participation operate, how they would like them to operate and their decision making about participation. We aimed to find out about barriers and factors that facilitated participation such as incentives, environment, communication and expectations.

We undertook a brief narrative review of relevant literature to help identify the key issues faced by each group, and incorporated the key findings into our interview schedules, and into our thinking about developing a practice model.

We selected two sites for each of the four user groups – homeless people with addiction problems, people from black and minority ethnic communities, people

with communication impairments, people with dementia. The primary criteria for selection was that each site should have some experience of involvement of people who use services so that most respondents would be able to draw on personal experience, rather than attempt to talk about abstract or hypothetical situations. The organisations were geographically spread throughout England.

We gathered background information on policies and services before interviewing managers, staff and people who use services at each site. A total of 41 people who use services, 20 frontline staff and 12 managers were interviewed. The transcripts of the interviews (some from audio recording, some from notes) were analysed to test our hypotheses about the mechanisms of involvement. We also identified what people understood by participation and the barriers to it and the factors enabling it to happen.

The research plans and findings were discussed by a reference group of people using services who are actively involved in developing participation for the target groups of this study. The model of integrated participation which arose from the findings (see Figure 1, below) was discussed with a sample of organisations participating in the research, and further refined. The model was also presented at two seminars at the SCIE Conference 2007 and the feedback from these sessions was taken into account.

Background issues

There is a gap in knowledge about how some groups of people who use services participate in social care services. Previous work has identified that while participation in services, including decision making at different levels, has developed for some groups, others remain excluded (Carr, 2004; Begum, 2005).

The existing research falls into two broad categories. First, there are accounts of the exclusion of certain groups from social care services including identification of the many barriers that prevent access (for example, Yu, 2000; Evans and Banton, 2001; Fountain and Howes, 2002; Parr et al, 2004;). Second, a number of studies report on initiatives which aimed to engage seldom-heard groups. Typically, these identify practices and contextual factors that have enabled participation (for example, Cook, 2003; Chahal, 2004; Cantley et al, 2005).

Policy context

The personalisation agenda represents a huge change in the way social care services are provided and funded. This new agenda presents both opportunities and challenges to people from seldom-heard groups.

The government has outlined what personalisation means for public services:

Personalisation is the process by which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and the services they receive. (Prime Minister's Strategy Unit [2007] HM Government policy review – Building on progress: Public services, London: Prime Minister's Strategy Unit, p 33)

There is a range of government papers and policies that have established a policy direction in which personalisation and self-directed support are key factors. These include:

- Independence, well-being and choice (2005).
- Our health, our care, our say: A new direction for community services (2006) reinforced the messages in the Green Paper for a stronger voice, more choice and control.
- Strong and prosperous communities: The local government White Paper (2006) set out cross-government ambition to transfer more influence and power to local people and local communities.
- Putting people first: A shared vision and commitment to the transformation of adult social care (2007) provided cross-sector confirmation of the direction and responsibility to deliver.

Putting people first sets out how central and local government, public sector professional leaders, providers and regulators will work together to transform adult social care. The vision for social care is that everyone who receives social care support will have choice and control over how that support is delivered. The main vehicle for delivering this vision is making personal budgets available to people who use services.

Who are 'seldom-heard' service users?

'Seldom heard' is a relatively new term which needs some clarification. For some time debates about user and public participation have referred to 'hard-to-reach groups' (for example, Cook, 2002). However, this label can be interpreted as suggesting that there is something about the individuals in these groups that results in them not engaging with social care services. An alternative approach is to focus on the responsibility of services and organisations to ensure that all people potentially using services have access to those services and can have their voices heard (Begum, 2005).

It is important for social care providers to consider which groups of people using services currently and potentially in their communities are seldom heard, making it necessary for providers to have local demographic knowledge. Identification and analysis of subgroups is a prerequisite for engaging with these groups. Service providers have a duty to ensure that all members of their communities have their right to services made a reality in practice.

Plenty to say but seldom heard

'Hello, my name is [removed for confidentiality]. I am a laryngectomee. My vocal chords were removed due to cancer over 12 years ago. For the past 7/8 years I have tried to be involved as a service user in various cancer, health and disability groups.

Sadly I find I am always the only person without "normal" communication. I am very aware of how the many people without – or [with] severely impaired – speech

are thoughtlessly lacking the support given to other visible impairments. We are not represented on decision-making bodies, no PAs [personal assistants] supplied to assist us, and communication aid supply limited.

Public services only contactable by telephone on the mistaken assumption that we can all use one. Vulnerability not recognised. It is so very easy for anyone to talk down or ignore a person who cannot TALK back loudly. The isolation of our daily lives is not understood.

Consultation meetings tend to be dominated by a minority of over-verbose speakers.' (from a request for help received by SCIE)

What is meant by 'participation'?

There is no single agreed definition of participation. A multitude of related terms further confuse the debate: engagement, consultation, involvement, inclusion, access, representation, etc. A lack of common understanding of what is meant by participation makes it difficult to pin down the problem and design solutions. Some work focuses on access to services and some on access to decision making about service and policy development including research.

There have been different approaches to conceptualising participation and attempts to make sense of its multi-dimensional nature. Some user-led organisations have focused on the distribution of power as a fundamental, defining characteristic of relationships between service providers and users. The desired outcome of participation then becomes a transfer of power from providers to people who use services or a greater sharing of power – a democratisation of services.

One practical implication of this model is that people who use services need to be influential, usually through direct involvement, at every level of decision making. As a result, considerable numbers of services users with sufficient capacity, time, skills and interest are needed in order to populate all the decision-making processes. This model implicitly includes an assumption that different types of participation can be arranged within a hierarchical structure, giving us the now-familiar 'ladders' metaphor (for example, Arnstein, 1969; Wilcox, 1995; Hart, 1997).

Recent work has attempted to move away from this hierarchy, with its implication that involvement in, or control of, top-level decisions should be the goal, to a 'whole-systems' approach (Wright et al, 2006; Moriarty et al, 2007). The 'whole system' consists of four different aspects of organisations and services which all need to be addressed simultaneously and welded together: culture, structure, practice and review. These four aspects are represented as interlocking jigsaw pieces. In terms of the whole-systems model, our research with seldom-heard groups can be placed where organisational culture and practice interlock.

Case study research findings

Getting involved

Some of the seldom-heard service users in this research were involved in service development and strategy via the processes of management and governance of services. Most, however, were not involved at this level, but still perceived themselves as being involved. Crucially for them their involvement in a service centred on their needs and priorities at that time. But as the case examples show, participatory practice at the everyday level provided an important foundation for involvement in service development and governance.

People who use services and staff, but especially the people using services, did not talk about participation or engagement. They talked more about 'getting involved' or simply what they were doing, which was mostly everyday activities such as meeting friends, going to a group, or learning new skills. In response to this we decided early in the project to ask people about how they got involved rather than about engagement or participation explicitly.

The concept of participation as an integral part of how an organisation works was identified in an evaluation of user involvement in the Leonard Cheshire Foundation. The report concludes that 'There is no body of concern that can be seen as "service user involvement" that is separate or isolated from all decision-making structures and processes' (Leonard Cheshire, 2005, p15).

'Getting involved' includes:

- getting support, information and advice from professional staff
- getting support, information and advice through sharing experiences with other people in the same situation
- helping others through mutual support, one-to-one or in groups
- helping others through volunteering
- making friends through joining groups and doing training courses
- enjoying themselves and having fun through shared experiences and activities such as games, dancing and outings
- learning skills such as cooking, typing, using email
- helping to improve services by giving feedback and completing questionnaires
- training professionals in communication methods
- finding out about and using complaints procedures in different services
- protesting about national policies
- taking part in forums of people who use services
- being a member of a staff selection interview panel
- giving views about policy and practice in an agency so that it can update and revise documents.

(Examples from case studies)

Models of participation

The services and projects which took part in this study operated within different policy and funding environments. While managers and staff felt some pressures which jeopardised their efforts to promote involvement, they often managed to create supportive environments. The managers and staff in all the settings were broadly supportive of developing the participation of seldom-heard groups. However, services and staff adopted different approaches to participation.

People who use services told the researchers many positive stories about how they were involved with these services in a wide variety of ways. They had built relationships with the staff and other people using services over time and appreciated being valued and treated with respect. Many reported that they enjoyed the sense of purpose they had in achieving things for themselves and through helping others. They also praised the balance between encouragement to get involved and to try new things, and the option to slow down or withdraw.

Significantly, the process of involvement was facilitated by skilled and committed staff. These staff recognised individual needs and respected people's need to address their immediate priorities. The key role of professional staff in enabling the participation of seldom-heard groups is reflected in the literature (see, for example, Beresford et al, 2006). Allan (2001) found that staff needed support and encouragement to utilise their existing skills and knowledge to develop better communication with people with dementia. In turn, effective communication led to involvement in different activities including consultation about services.

'Everyday' participation

The picture that emerged in all the services, except one which was specifically designed to involve people who use services in training professionals, highlighted two approaches to participation. The first approach viewed participation as a specific activity which organisations and staff attempted to plan and carry out in addition to delivering services. The second approach made no distinction between service delivery and participation: participation was part and parcel of everyday work, services, activities, relationships and events. Because of the way that participation was integrated, it was difficult for some staff and people using services to articulate it as a separate thing that we, the researchers, wanted to talk about.

One feature of the first perspective was that, as a separate activity, participation often focused on involvement in a decision-making process about current or future services, for example, feedback from people using services, or expressing preferences about plans. The need for this kind of consultation or participation was often in response to management, policy or funder agendas. It was a requirement in funding applications, and perceived to be a 'good thing', yet kept as a discrete activity. In contrast, the second perspective placed people who use services at the centre of the process. In this case the relationship between people who use services, individually and collectively, and the service, and in particular the staff, encompassed a wide variety of elements. One of these elements was about meeting immediate needs.

Other research with black disabled people has identified the importance of meeting people's basic needs as a priority before attempting to engage in research and development projects (Singh, 2005). Similarly, research on ways of consulting with people with dementia found that 'Whatever was done, it was crucial that the emphasis was on providing opportunities for the person to express themselves, rather than adhering to a specific procedure or technique' (Allan, 2001, p 2).

For some people who use services on some occasions an element of their relationship with the staff and the service focused on service or policy development, but only when it was an issue for them. Two examples illustrate this point:

- A small group of people with dementia had been meeting once a week as part of a computer project. Their group had social and mutual support benefits for the members in addition to creating a website designed for people with dementia. One issue the group discussed concerned a National Institute for Clinical Excellence decision about dementia treatment. As a result the group, some of whom had high levels of impairment, decided to take part in a demonstration in central London.
- Older people from Greek, Afro-Caribbean and Asian communities met in groups at a day centre. They attended their groups to get out of the house, meet friends, have lunch or a massage, do activities and get advice. Group members raised issues about standards of home care with staff who supported them to complain to social services. Similarly, problems with the council's transport service were resolved by group members writing letters asking for changes to the service. The problems were resolved within three days of the complaints being made.

We suggest that these people's 'participation' in civic life through demonstrating, and in service development through complaining, would have been unlikely to happen if they had not been part of a group already.

Our central argument so far is that everyday participation is the bedrock of involvement in other aspects of services, for example in their development, management and governance. However, it is not sufficient for people who use services to feel valued and develop the confidence to take part in decision making about services. It is also necessary for organisations to enable access to decision-making structures and processes.

Some interviewees in our study clearly had the skills, knowledge and confidence to take part in management and development of services. One case study focused on the involvement of people with communication impairments due to aphasia¹ as trainers for other professionals. What was striking about this case was that their experiences of getting involved in the group of people who use services – people who eventually trained as trainers themselves and delivered courses to communications professionals were very similar to those of people who were getting involved in services and groups primarily aimed at delivering support and advice. For example, they were uncertain at first about their involvement and abilities, needed support to gain confidence and found being part of a group of people using services helpful, and

¹ Aphasia is a communication disorder where a person loses the ability to use and understand language.

the staff supporting them were skilled, committed and met their access needs (Byng et al, 2002).

Other agencies also provided access to service and policy development, for example through recruitment panels for staff, management committees, forums of people who use services, satisfaction questionnaires and volunteer roles.

Inclusion

Participation can usefully be redefined to include a variety of different activities rather than a narrow set of practices such as consultation and forums of people who use services.

This integrated, everyday approach to participation had emerged from the efforts of staff to build strong relationships with service users which developed trust, mutual understanding and respect. The interviews with people who use services revealed that they valued the way that staff acted in ways that were:

- inclusive
- positive and optimistic about people who use services
- non-judgemental.

The importance of understanding values and incorporating them in the practice model is that they act as a framework in uncharted territory. The process of translating values into practical action in different situations and over time means that practices are developed and tested to ensure they are effective.

The variety of the perspectives of people who use services on getting involved demonstrated that it is important not to make assumptions about why or how an individual could be involved. The value base described above provides a foundation for staff to recognise the variety of individual situations. People who use services spoke of a number of issues that were personal to them and that affected whether, when and how they got involved, including:

- their own capacity in terms of energy or motivation
- their identification with a service or group intended for a specific part of the community
- their cynicism about whether services could help or genuinely wanted their views
- their fear that criticism of services would affect current or future access to services or endanger financial support for services.

Other studies have demonstrated the importance of respect for people who use services. Bamford and Bruce (2000) asked people with dementia about the outcomes they wanted from services and identified as important: autonomy, having a say, feeling valued and respected and being treated as a normal person. Focusing on the needs and priorities of individuals with aphasia and identifying the values that underpin this approach have led to a new model of practice for communication professionals (Byng et al, 2002).

Translating values into practical actions

- Members of a group for people with dementia reported that a support worker put no pressure on anyone to get tasks done or progress, and was prepared to repeat instructions as many times as necessary for them to complete tasks on the computer themselves.
- Residents of a hostel for people who are homeless and have addiction problems described how staff encouraged them to go to activities and on courses, and that the manager believed in and was optimistic about them.
- People with communication impairments felt valued as a result of being trained to become communication trainers. They liked being involved in something that 'helps them and ... helps us'. During the training they had time to talk and to laugh and because there was adequate time they knew that 'when you make mistakes it doesn't matter'.
- A person with dementia who was a volunteer suggested that he should be able to join in staff activities such as preparing lunch rather than remain in a 'service user' role. The staff used their commitment to inclusion and to giving people with dementia control as a basis for reflecting on the issues raised and finding ways of accommodating this person's aspirations and expectations.

Without the value base described in the above examples, it is likely that existing rules and boundaries regarding, for example, roles, risk and health and safety would have prevented exploration of participation in these situations.

Practicalities of participation

There is already a substantial amount of guidance on the importance of ensuring access to information, services, venues, events and debates through getting the practicalities right (SCIE, 2005). The importance of practical access was echoed in this study.

People who use services and staff recognised the need for good practical arrangements. We suggest that in the cases we examined, organising the practicalities had become second nature or part of the everyday approach to participation. It appeared that getting the practical side right flowed from the value base described above and the staff's commitment to it.

Enabling practical access

Communication, meetings, transport

Deaf/blind, deaf and hard of hearing people found it useful to have interpreters who were not staff of the agency providing services, and all information in plain language with pictures to back up text. The organisation of meetings was also important to them with plenty of notice about arrangements, changes or cancellations, and clear explanations of what meetings were about and what was expected of them. They also said it helped if meetings were not too long.

Transport was a big issue for this group, with nervousness about unreliable transport and, for some, fear of how they were treated by members of the public, affecting their willingness to get involved in some events.

Planning joint work with people who use services

The researchers in this study modelled good practice based on our experience as a team, which was confirmed by our findings, and were able to draw on our experiences as practitioners as well as researchers.

One researcher made a number of visits to an older people's centre to meet staff and members of the different black and minority ethnic groups there. This paved the way for the research interviews and gave time to organise interpreters and to discuss appropriate recognition and payment for their participation.

The researcher working with people with communication impairments and people with dementia discussed options for interviewing people who use services and staff. This led to a joint decision to use small group interviews of three or four people rather than one-to-one sessions. This method enhanced communication through the support of members who already knew each other. For one person who used very little speech, the group setting gave the opportunity for her to indicate agreement and disagreement with her colleagues' contributions. In a one-to-one session she would have been almost completely excluded from the process.

We also took a flexible approach to the research reference group. One member required a specialist typist/interpreter. The availability of this specialist was limited so we arranged separate meetings to suit this group member.

Learning about cultures

A centre for older people acts as a base for three different groups of older people: Greek, Asian elders and Caribbean pensioners and friends. The centre staff had built up membership of these groups through outreach work and offering relevant advice, information and support services.

The groups used festivals and cultural events such as Eid, saints' days and Diwali, to invite members of other groups to join with them and share food and customs. This led to opportunities for learning about each other's cultures and built mutual understanding and opportunities for wider collective involvement, for example, making complaints about the local authority's transport service.

This example reflects some of the features of a 'mainstreaming' approach to equalities such as responding to the complexities of diversity (Blakey et al, 2006) and focusing on service users' priorities in service design (Bowes, 2006).

Working with uncertainty

This research identified that staff and people who use services had to navigate their way through a number of uncertainties and tensions to ensure that people could get involved and achieve some positive outcomes. Table 1 sets out some of the tensions that emerged from our research.

Table 1: Tensions		
The need to have a clear purpose for any service, group or event	↔	A variety of choices about what to get involved in
Clear messages about what was expected of people who use services	↔	Flexibility and adaptability of services, projects
Meeting output-based external expectations about participation, for example, number of people finishing a course	↔	Respecting individual service user circumstances, priorities and needs
Meeting management demands for consultation on policy or practice	↔	Focusing on the process of developing relationships and trust
Encouraging people who use services to get involved and having high expectations about what they could achieve	↔	Being realistic about individual capacity and motivation and avoiding putting someone under pressure
Expecting staff, as professionals, to be expert, make judgements, take responsibility and decisions	↔	Incorporating expertise and experience of people who use services, and sharing responsibility and decision making with them
Participation as an activity allocated to specific staff, designed to meet targets set by funders	↔	Participation as part of everyone's work

Uncertainty about where the process of involvement would lead and about eventual outcomes was a feature of service users' accounts. Reflecting on recent experience, many people using services had a good idea of why they were involved with a service or group and what they got out of it. However, they were less clear about what they had expected. The following examples illustrate the wide variety of reasons why people get involved with services, activities, courses and groups.

'There's no end of laughs.' (member of dementia group)

'I want to be able to help, not be a patient.' (member of communication training group)

'I have the confidence to get back to employment.' (member of training course for homeless people with addiction problems).

People who use services also wanted clear messages about what was expected of them, what they could expect from participation in a service or event and what feedback they would get about the outcomes. The challenge for staff and services was to find ways of responding to these multiple expectations and needs.

Changing role of professionals

The ethos of everyday, inclusive participation of people who use services required staff to incorporate the expertise and experience of people who use services in decision making. Everyday participation also meant that staff and people who use services shared responsibility and decision making.

Traditionally, however, many professionals are trained and recruited to be experts with the specialist knowledge and skills to make judgements about the best interests of their clients. An everyday participatory approach blurs the boundaries between the roles of professionals and people who use services. One user observed that 'the environment is very informal and volunteers and staff are mingling around [so] there's very little dividing'.

There is evidence from research that professional staff are positively exploring these newly blurred boundaries. For example, social movements and consumer power combine to challenge professional roles. In response, professionals are having to adjust and shape their knowledge and skills to meet specific needs and priorities in particular circumstances, for example in relation to language and culture (Foster and Wilding, 2000; Byng et al, 2002; Dominelli, 2004). Another study identifies the need for professionals to have a 'breadth of vision' which allows them to operate outside the conventional demands of their programme or job role (Merighi et al, 2005). A study of involvement of people with dementia in service evaluation concluded that staff need to be able to take a critical stance in relation to the care they provide (Fook et al, 1997; Cheston et al, 2000). We would argue that this approach and resulting practices are a requirement of developing an everyday approach to participation.

However, further tensions may arise since, while participation can make relationships between staff and people who use services more adversarial, there is a desire that new partnerships will emerge involving policy makers, professionals, managers and people who use services, based on mutual respect and trust (Foster and Wilding, 2000).

Protected spaces

Everyday participation took place in groups, services, teams and organisations which were protected from certain practices which undermine this approach. The process of enabling everyday involvement of people from seldom-heard groups required insulation from tick-box approaches to the involvement of people who use

services, demands of programme monitoring or funding conditions and unsupportive organisational environments.

Two key enabling factors identified by many staff and people who use services were time and money. The process for developing strong relationships based on trust, respect and mutual understanding required a considerable amount of time. This implied that time-limited projects, services and consultations (including this research project) will always have limited scope for engaging seldom-heard groups.

There was a need to finance staff time to develop relationships with seldom-heard service users both within mainstream services and specialist organisations. In addition, money was needed to ensure practical access to information, meetings, services, people, events etc. In some cases lack of access was not simply about finance but also the supply of expertise, for example British Sign Language (BSL) interpreters trained to the right level. Some barriers to participation experienced by people who use services, and some good practice responses, are set out in the two boxes below.

Barriers experienced by people who use services

Attitudinal barriers

- staff treating adults using services as if they were inferior
- perception that some staff do not believe in the potential of the people they are supporting
- experiencing harassment when using public transport.

Organisational barriers

- not enough thinking time for some people with impairments
- communication in meetings too fast for some communication methods
- emphasis on meetings, excluding people who operate better in other situations
- too much reliance on computer-based communication and reference to websites, and not enough thought given to other forms of communicating
- finding people to engage with, especially when service use is episodic and service users have transient lifestyles
- practicalities of communication, for example, cost, technology, training, skills
- content of communication, for example, the extent to which different parties have different perspectives or are on different wavelengths.

Cultural barriers

- individual perception that a service or group is 'not for me'
- fear that complaining or criticising services will jeopardise the service or an individual's access to it
- meetings or events where 'lots of people talking in the same room' make communication or understanding difficult for some people
- concern about being called or labelled a 'service user'.

Practical barriers

- lack of interpreters
- lack of information about rights and services

- Poor acoustic environments for communication, for example, too much background noise
- Lack of accessible transport and finance for it
- documents that are too long, complicated and not in plain language
- difficult group dynamics and relationships between people who use services becoming a disincentive for some service users; for example, one or two dominating persons
- lack of clarity about, for example, how much power and influence a group of people who use services has within an organisation
- 'Picking and choosing' service users to 'get the right answers', for example, in meetings with MPs.

Good practice to overcome barriers

- treating people with respect and valuing individual contributions to build good relationships and trust
- offering face-to-face communication and encouragement to help build relationships
- describing clearly what someone can expect from getting involved and what they are expected to contribute
- making sure people know they can say 'no' to getting involved, and still get involved in the future
- engaging people with an activity or task which provides a stimulating focus and is not directly about service or policy improvement
- offering a variety of activities and ways to get involved, for example, getting help, helping others, learning, having fun, socialising
- allocating sufficient resources to ensure good access in terms of communication, transport, meetings, support and payment.

Putting yourself in the shoes of a person using services

Questions that people may have in mind when deciding about getting involved:

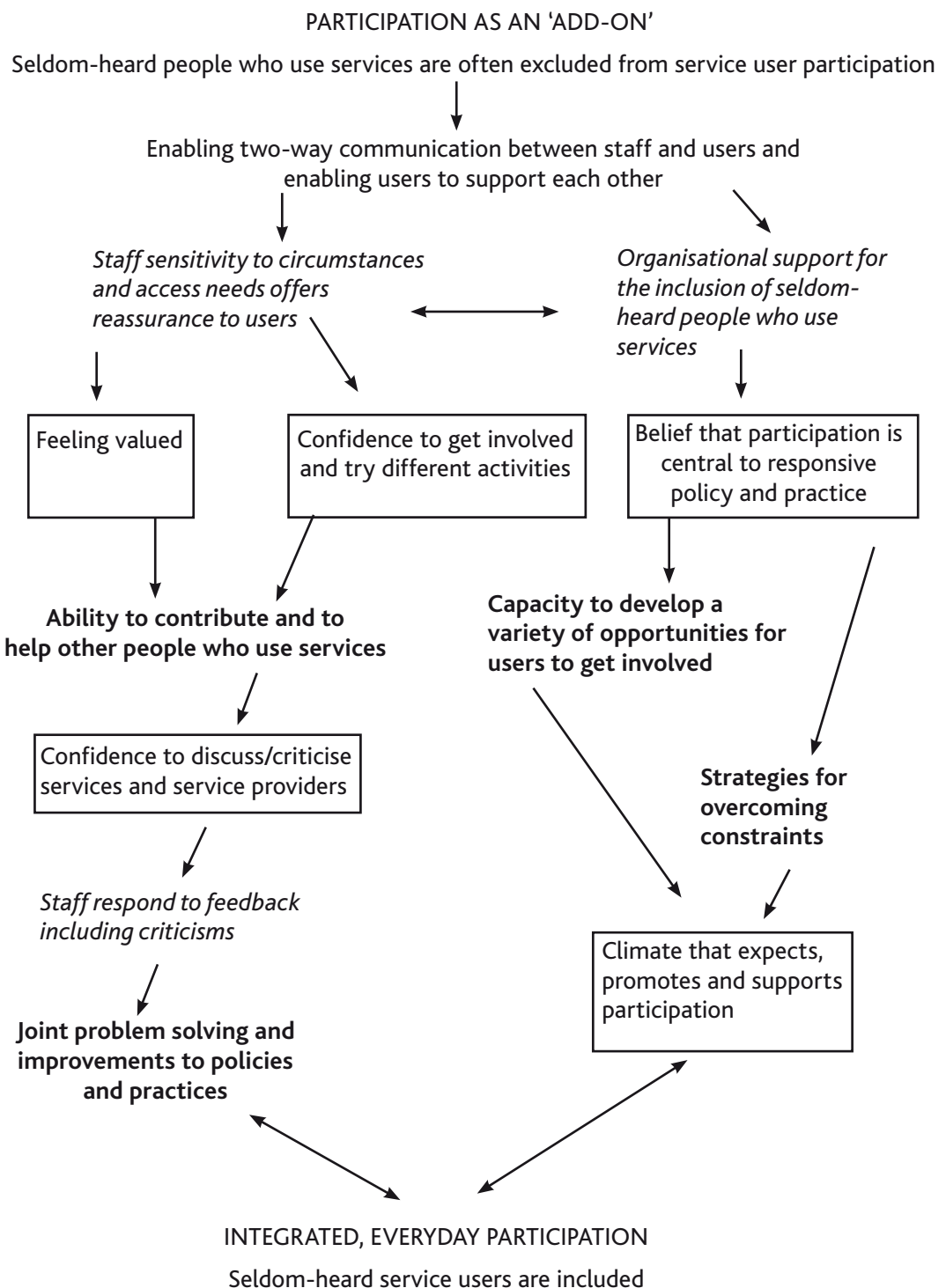
- Will I be treated with respect?
- What will I get out of it?
- What can I offer?
- Can I make a difference?
- Are these opportunities relevant, interesting and enjoyable?
- Will I be of help to others like me?
- Will I have problems with communication, transport or other support?
- Can I talk to someone to find out more?

A model for everyday participation

From the case study research we developed a practice model for everyday participation.

In the model below, the sentences in the **boxes** are the factors which enable service providers and people who use services to achieve everyday participation. The sentences in *italics* are how the service providers and users work together. The sentences in **bold** type are the response to the social interaction or activity.

Figure 1: Practice model for everyday participation



The model shows how people who use services are placed at the centre of a framework for everyday participation. People who use services are more likely to achieve the outcomes they identify when organisations:

- recognise and respect the circumstances and capacity of each individual service user or potential service user
- adopt an everyday participatory approach which integrates participation into all aspects of a service or group or organisation
- work from a value base which is inclusive, positive about the potential of people who use services and non-judgemental
- create a policy, funding and management context which encourages a participatory approach to flourish
- recruit and train frontline staff, volunteers and managers to understand and implement an everyday participatory approach in a practical way
- provide a wide choice of ways of getting involved
- accept uncertainty about the likely outcomes of involvement including a wide variety of possible outcomes and a mix of 'successes' and 'failures'
- accept that people who use services have a very wide variety of expectations about what outcomes may derive from getting involved with a service or group or activity
- build mutual understanding between staff and people who use services
- view involvement, engagement and participation as a two way relationship that may wax and wane over time
- redefine an organisation's or service's goals and expectations of participation or 'service user involvement' in line with users' goals and expectations
- address new situations openly with people who use services and staff together.

The following case study demonstrates what everyday participation can mean in practice. In this case study, the work of a day opportunity centre for people with dementia, which is open seven days and three evenings per week, is described by the centre organiser and by people who use services.

Everyday participation in practice

Centre organiser's views:

'To consult service users there are monthly members' meetings with a service user as chair. The week before the meeting staff prompt and remind people that the meeting is coming up. They have a sign over the fireplace to ask people if they want to include anything on the agenda. People participate well.

We plan nothing here. It is an arrogance to plan someone's day for them. We go with the flow, people themselves initiate. Staff would suggest but not herd. Members may choose to do nothing.

Two members of the group are also part of the Scottish Dementia Working group, and they are on two local committees.'

'The centre started off with a ratio of six members of staff to nine service users, it is now four staff. Without the staff we couldn't do what we do.

People are supported to do absolutely anything and everything – go to the bank, shopping, attend appointments, maintain life skills, anything.

Our service manager four-and-a-half years ago had a rare vision, she was crazy and brave! She was so tuned in, she wanted to change the ethos of a day centre, wanted to give people opportunities. If I ever feel that slipping away I make sure I find it again.

It seems too easy to say we just maintain involvement. It's quite seamless. Don't know where the service user ends and the staff begins. We have low staff turnover. For staff it's the "it thing". You've got to be "in it" while you're doing it. You could train people for ever and they wouldn't necessarily have "it". Tune in and go with it. You need to go to where people with dementia are [and] sometimes you don't bring all of yourself back.

When we had staff off sick, we had a replacement staff member from Paisley, it just wasn't working. Three service users complained, he was not "in it". He was sent back. It was good they felt they could do this.

One man was refused by his local church choir. We helped him to lobby the church. Barriers are lack of awareness by others about supporting people with dementia.

Local authorities are more aware that people with dementia are here. They know that if they ride roughshod over people the centre will challenge any decisions.

We have a no locked-door policy, instead we have a wind-chime that alerts us if people are coming in or out. In four-and-a-half years we haven't lost anyone.'

Feedback from people who use services:

'It's a good atmosphere. The staff are great.'

'It's good for you. It's got to be so it makes you want to come back. There's choice. They [staff] are never weary, they share your interests and ideas.'

'I was apprehensive. But they make you feel welcome. You've got to try. I've never looked back.'

'It's a good club. You make friends here.'

'Yes I would recommend it, it would make you relaxed.'

Three more members were asked to take part in the interviews but decided to continue with a dominoes competition instead.

Conclusion

Social care services are going through a period of rapid change. As the implementation of the personalisation agenda proceeds the issues discussed in this report will take on a renewed urgency. Everyone has the right to be involved in planning and decision making about their everyday lives and the services they receive. The voices of some people, however, are less likely to be heard. During periods of rapid change and innovation seldom-heard service users may find it even more difficult to communicate their requirements. This report suggests that seldom-heard users of social care services can become engaged if practitioners and managers adopt an inclusive approach to participation.

The report describes the value base and characteristics of everyday participation, the organisational tensions and barriers that hinder best practice, and practical action to overcome barriers. The proposed practice framework, summarised in the visual model, can help practitioners and managers move from participation as an add-on to an integrated, everyday way of working.

References

- Ahmed, S., Hussain, M. and Vournas, G. (undated) 'Consultation with "hidden" and hard-to-reach groups: methods, techniques and research practice', Trescom Research and Consultancy Limited (available at www.laria.gov.uk/content/features/68/feat1.htm, accessed September 2006).
- Allan, K. (2001) *Communication and consultation: Exploring ways for staff to involve people with dementia in developing services*, Bristol: The Policy Press.
- Arnstein, S. (1969) 'A ladder of citizen participation in the USA', *Journal of the American Institute of Planners*, vol 35, no 4, pp 214–24.
- Bamford, C. and Bruce, E. (2000) 'Defining the outcomes of community care: the perspectives of older people with dementia and their carers', *Ageing and Society*, no 20, pp 543–70.
- Begum, N. (2005) 'I'm not asking to live like the Queen.' *The vision of service users (or potential service users) and carers who are seldom heard on the future of social care for adults in England, Consultation response*, London: Social Care Institute for Excellence (available at <http://www.scie.org.uk/publications/details.asp?pubID=103>, accessed January 2008).
- Beresford, P., Adshead, L. and Croft, S. (2006) *Service users' views of specialist palliative care social work*, Joseph Rowntree Foundation Findings, November, York: Joseph Rowntree Foundation.
- Blakey, H., Pearce, J. and Chesters, G. (2006) *Minorities within minorities: Beneath the surface of South Asian participation*, York: Joseph Rowntree Foundation.
- Bowes, A. (2006) 'Mainstreaming equality: implications of the provision of support at home for majority and minority ethnic older people', *Disability and Society*, vol 40, no 7, pp 739–57.
- Butt, J. and Dhaliwal, S. (2005) *Different paths: Challenging services: A study of the housing experiences of black and minority ethnic disabled and deaf people*, London: Habinteg Housing Association (www.differentpaths.org.uk/downloads/research_report.pdf, accessed September 2006).
- Byng, S., Cairns, D. and Duchans, J. (2002) 'Values in practice and practising values', *Journal of Communication Disorders*, no 35, pp 89–106.
- Cantley, C., Woodhouse, J. and Smith, M. (2005) *Listen to us, involving people with dementia in planning and developing services*, Newcastle: Newcastle Dementia North/Northumbria University.
- Carr, S. (2004) *Has service user participation made a difference to social care services?*, Position paper no 3, London: Social Care Institute for Excellence (www.scie.org.uk/publications/positionpapers/pp03.asp).

- CCNAP (Community Care Needs Assessment Project) (2001) *'Asking the experts' – a framework to involving people in shaping health and social care services* (www.ccnap.org.uk/Framework/askingtheexperts.PDF, accessed March 2007).
- Chahal, K. and Ullah, A. (2004) *Experiencing ethnicity: Discrimination and service provision*, York: Joseph Rowntree Foundation 914 (www.jrf.org.uk/KNOWLEDGE/findings/foundations/pdf/914.pdf, accessed September 2006).
- Cheston, R., Bender, M. and Byatt, S. (2000) 'Involving people who have dementia in the evaluation of services: a review', *Journal of Mental Health*, vol 9, no 5, pp 471–9.
- Communications Forum (undated) *Living with communication impairment, a study commissioned by the Communications Forum* (www.communicationsforum.org.uk/Docs/Living%20With%20Communication%20Impairments.pdf, accessed October 2006).
- Cook, D. (2002) 'Consultation, for a change? Engaging users and communities in the policy process', *Social Policy and Administration*, vol 36, no 5, pp 516–31.
- Cook, J., Maltby, T. and Warren, L. (2003) 'Older women's lives and voices: participation and policy in Sheffield', ESRC Growing Older Programme research findings 21 (www.growingolder.group.shef.ac.uk/Go_Findings_21.pdf, accessed September 2006).
- Dominelli, L. (2004) *Social work: Theory and practice for a changing profession*, Cambridge: Polity Press.
- Evans, R. and Banton, M. (2001) *Involving black disabled people in shaping services*, Findings D61, York: Joseph Rowntree Foundation (www.jrf.org.uk/knowledge/findings/socialcare/pdf/D61.pdf, accessed March 2007).
- Fook, J., Ryan, M. and Hawkins, L. (1997) 'Towards a theory of social work expertise', *British Journal of Social Work*, no 27, pp 399–417.
- Foster, P. and Wilding, P. (2000) 'Whither welfare professionalism', *Social Policy and Administration*, vol 34, no 2, pp 143–59.
- Fountain, J. and Howes, S. (2002) *Home and dry? Homelessness and substance use in London*, London: Crisis.
- Hart, R. (1997) *Children's participation: The theory and practice of involving young citizens in community development and environmental care*, New York/London: Earthscan/UNICEF Publications.
- McLean, C., Campbell, C. and Cornish, F. (2003) 'African-Caribbean interactions with mental health services in the UK: experiences and expectations of exclusion as (re)productive of health inequalities', *Social Science and Medicine*, vol 56, no 3, pp 657–69.

- Merighi, J., Ryan, M., Renouf, N. and Healy, B. (2005) 'Reassessing a theory of professional expertise: a cross national investigation of expert mental health social workers', *British Journal of Social Work*, no 35, pp 709–25.
- Moriarty, J., Rapaport, P., and Beresford, P. (2007) *The participation of adult service users, including older people, in developing social care* (www.scie.org.uk/publications/practiceguides/practiceguide11, accessed 3 December).
- Parr, S., Byng, S., Barnes, C. and Mercer, G. (2004) *Social exclusion of people with marked communication impairment following stroke*, Findings 814, York: Joseph Rowntree Foundation.
- Singh, B. (2005) *Making change happen for black and minority ethnic and disabled people*, Joseph Rowntree Foundation Findings 0495 (www.jrf.org.uk/Knowledge/findings/socialcare/0495.asp, accessed September 2006).
- SCIE (Social Care Institute for Excellence) (2005) *How to make events accessible*, (www.scie.org.uk/publications/misc/accessguidelines-events.pdf, accessed January 2008).
- Surrey Alcohol and Drugs Users' Forum (1995) *Who knows best? Developing user involvement in substance misuse services*, Surrey: Time is Right Publications.
- Warburton, D. (2006) *Evaluation of 'Your health, your care, your say', Final Report*, Department of Health (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndFramework/DH_4138622, accessed March 2007).
- Wilcox, D. (1995) *Framework to effective participation*, York: Joseph Rowntree Foundation
- Wright, P., Turner, C., Clay, D. and Mills, H. (2006) *The participation of children and young people in developing social care*, Practice Framework 06, London: Social Care Institute for Excellence (www.scie.org.uk/publications/practiceframeworks/practiceframework06/files/pg06.pdf, accessed March 2007).
- Yu, W.K. (2000) *Meeting the needs of Chinese older people*, Joseph Rowntree Foundation Findings 920 (www.jrf.org.uk/knowledge/findings/socialcare/920.asp, accessed September 2006).

Further reading

- Afshar, H., Franks, M., Maynard, M. and Wray, S. (2001) 'Empowerment, disempowerment and quality of life for older women', *Generations Review*, vol 11, no 4.
- Afshar, H., Franks, M., Maynard, M. and Wray, S. (2002) 'Gender, ethnicity and empowerment in later life', *Quality in Ageing*, vol 3, issue 1, pp 27–34.
- Allan, K. (2002) 'Focusing, reflecting and exploring how to communicate effectively', *Journal of Dementia Care*, vol 10, no 5, pp 16–17.
- Barn, R. (2003) *Social care needs and concerns: A study of older Bangladeshi women in Tower Hamlets*, London: Royal Holloway University of London.
- Begum, N. (2006) *Doing it for themselves: participation and black and minority ethnic service users*, London: Social Care Institute for Excellence (available at www.scie.org.uk/publications/reports/report14.pdf, accessed September).
- Bott, S. (1997) 'Involving physically disabled users in service planning and delivery: Shropshire as a case study based on two national projects', *Research Policy and Planning*, vol 15, no 2, pp 38–42.
- Butt, J. and O'Neil, A. (2004) *Let's move on*, Race Equality Unit (www.jrf.org.uk/bookshop/eBooks/185935176X.pdf, accessed September 2006).
- Chau, R. (2007) *The involvement of Chinese older people in policy and practice: Aspirations and expectations*, York: Joseph Rowntree Foundation.
- Corr, C. (2002) 'Reaching the "hard to reach"', Paper presented at a conference on 'Problem drug use and homelessness: Two faces of social exclusion', Dublin Castle, 18 July.
- Cox, G. and Lawless, M. (1999) *Wherever I lay my hat ... a study of out of home drug users*, London: The Research Office, Merchant's Quay Project.
- Daker-White, G., Beattie, A., Means, R. and Gilliard, J. (2002) *Serving the needs of marginalised groups in dementia care: Younger people and minority ethnic groups, Final Report May 2002*, Bristol: University of the West of England and Dementia Voice.
- Elliot E., Watson, A. and Harries, U. (2002) 'Harnessing expertise: involving peer interviews in qualitative research with hard-to reach populations', *Health Expectations*, vol 5, no 2, pp 172–8.
- Greater London Authority (2005) *Lessons learned, some approaches, tools and good practice for improving drug user involvement*, London: Greater London Authority.

- Harris, J. and Bamford, C. (2001) 'The uphill struggle: services for deaf and hard of hearing people: issues of equality participation and access', *Disability and Society*, vol 16, no 7, pp 969–79.
- Hubbard, G., Cook, A., Tester, S. and Downs, M. (2002) 'Beyond words: older people with dementia using and interpreting non-verbal behaviour', *Journal of Aging Studies*, vol 16, no 2, pp 155–167.
- Jones, L., Atkin, K. and Ahmad, W.I.U. (2001) 'Supporting Asian deaf young people and their families: the role of professionals and services', *Disability and Society*, vol 16, no 1, pp 51–70.
- Joseph Rowntree Foundation (1999) *Choice, dementia and people with learning difficulties*, Findings D19, York: Joseph Rowntree Foundation.
- Law, J., Bunning, K., Byng, S., Farrelly, S. and Heyman, B. (2005) 'Making sense in primary care: leveling the playing field for people with communication difficulties', *Disability and Society*, vol 20, no 2, pp 169–84.
- Leonard Cheshire (2005) *Service use involvement in Leonard Cheshire, December 2005*, London: Leonard Cheshire Foundation.
- Murphy, J., Tester, S., Hubbard, G., Downs, M. and MacDonald, C. (2005) 'Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool', *Health and Social Care in the Community*, vol 13, no 2, pp 95–107.
- Parr (undated) *Living with communication impairment*, Communications Forum (www.communicationsforum.org.uk/Docs/Living%20With%20Communication%20Impairments.pdf, accessed September 2006).
- Rabiee, P., Sloper, P. and Beresford, B. (2005) 'Doing research with children and young people who do not use speech for communication', *Children and Society*, vol 19, no 5, pp 385–96.
- Rai-Atkins, A. (2002) *Mental health advocacy for black and minority ethnic users and carers*, Findings 352 (www.jrf.org.uk/knowledge/findings/socialcare/352.asp, accessed September 2006).
- Robson, P. and Locke, M. (2002) *Changing voices, involving people with dementia in the Alzheimer's Society: Learning to live with dementia final evaluation report*, September, internal report.
- Taylor, G. (1999) 'Empowerment, identity and participatory research: using social action research to challenge isolation for deaf and hard of hearing people from minority ethnic communities', *Disability and Society*, vol 14, no 3.

Valios, N. (2006) 'Communication breakthrough' (www.communitycare.co.uk/Articles/Article.aspx?liArticleID=53124, item posted on message board 09 March 2006).

Vernon, A. (2002) *Users' views of community care for Asian disabled people*, Joseph Rowntree Foundation Findings 752 (www.jrf.org.uk/knowledge/findings/socialcare/pdf/752.pdf, accessed September 2006).

Warren, L., Cook, J. and Maltby, T. (2002) 'Working with older women from communities in Sheffield: methods issues', ESRC Growing Older Programme Newsletter issue 4 (www.growingolder.group.shef.ac.uk/Newslet4.pdf, accessed September 2006).

Seldom heard: Developing inclusive participation in social care

This position paper provides a practice framework to help practitioners and managers of social care services enable the inclusive, everyday participation of people from 'seldom-heard' groups

All SCIE publications and resources are free.

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
www.scie.org.uk
Registered charity no. 1092778
Company registration no. 4289790