



Listen to us:

Involving people with dementia in
planning and developing services

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CONTENTS

EXECUTIVE SUMMARY	3
Acknowledgements	5
PREFACE	6
Introduction	6
Identifying and developing good practice.....	6
Using this guide	8
1. CONTEXT AND CHALLENGES	9
Introduction	9
People with dementia.....	9
The policy context.....	9
The challenge of involving people with dementia.....	11
2. WHAT 'INVOLVEMENT' INVOLVES	12
Introduction	12
What we mean by 'involvement'	12
Approaches to involving people with dementia.....	15
Key points about dementia involvement.....	17
3. MANAGEMENT MATTERS	21
Introduction	21
Values and principles	21
Origins	21
Organisational arrangements	22
Resources.....	22
Establishing the baseline.....	23
Support, influence and impact.....	23
The approach	24
Ethical issues.....	25
Staffing	25
Staff support and practice development	28
Monitoring, review and evaluation	29
Key points for management.....	29
4. PRACTICE MATTERS	30
Introduction	30
Marshalling support.....	30
Planning the activity	30
Clarifying who will participate	31
Inviting people with dementia to participate.....	32
Working with family members	32
Ensuring ethical practice.....	33
Communicating with people with dementia	35
Involving individuals as consultants or advisors.....	38
Running group events and activities.....	38
Practice review and development.....	44
Key points for practice.....	44
CONCLUSION	47
References	48
Appendix 1 Further reading	51
Appendix 2 Useful resources	56

LIST OF TABLES, BOXES, FIGURES AND EXAMPLES

Table 1	The case study sites	7
Box 3.1	Involvement worker qualities, skills and experience	28
Box 4.1	Questions for staff in planning involvement activities	31
Box 4.2	Working with family supporters in involving people with dementia	33
Box 4.3	Suggestions about dealing with consent and other ethical issues	34
Box 4.4	Suggestions for supporting people as consultant or advisors	39
Box 4.5	Selecting a venue	40
Box 4.6	Suggestions for good facilitation	42
Box 4.7	Developing a reflective diary	45
Figure 2.1	Levels of influence and service stakeholders	14
Example 1.1	Journeys of empowerment	10
Example 2.1	Impact at different organisational levels	15
Example 2.2	Individual consultation	16
Example 2.3	Group consultation	18
Example 2.4	Participation	19
Example 2.5	Collective action	20
Example 3.1	Getting started	26
Example 3.2	Recognising staff efforts	28
Example 4.1	A relative facilitating the involvement of a person with dementia	32
Example 4.2	Ethical issues	34
Example 4.3	Communication for people with dementia	35
Example 4.4	Communication skills: what people with dementia need	36
Example 4.5	Being prepared to innovate	37
Example 4.6	Keeping a record	43
Example 4.7	The importance of follow up action	44

EXECUTIVE SUMMARY

The numbers of people with dementia are increasing and public awareness of dementia and its impact on people's lives has been growing. Despite this raised profile, people with dementia have remained a socially marginalized group. One aspect of their social exclusion has been their virtual absence from the mainstream service involvement initiatives of health and social care. This Executive Summary provides a brief overview of the main messages from a service development guide. The guide was produced by Dementia North as part of a Department of Health funded development project to explore how people with dementia can be involved in service planning and development.

WHY INVOLVE PEOPLE WITH DEMENTIA?

- The involvement of people with dementia has lagged behind the development of involvement work with other groups. This is no longer acceptable.
- As our understanding of dementia develops, growing attention is being paid to how we can better 'hear the voice of the person with dementia'.
- When people with dementia are enabled to communicate, they have important things to say about how dementia affects them, and about what they consider important about their present and future lives, including how services should meet their health and social care needs.
- The challenge of involving people with dementia is in essence the challenge of addressing their social exclusion.

WHAT DOES 'INVOLVEMENT' INVOLVE?

- The involvement of people with dementia should be founded on values of personhood, relationship and citizenship, and on the principles of ethical practice.
- Involvement activities with people with dementia can take place at a variety of organisational levels with purposes or aims ranging from influencing the operation of individual services to influencing social attitudes nationally and internationally.
- Involvement can have personal benefits for people with dementia who often report increased self-esteem and confidence arising from being included in involvement activities and feeling that they have something to contribute.
- Approaches to involving people with dementia include individual consultation, group consultation, participation and collective action. With each of these approaches a number of activities or methods can be used.
- It is important to recognise that some involvement activities are more empowering of people with dementia than others.
- Many existing dementia involvement initiatives have been service initiated with people with dementia being involved more as "passive suppliers of opinion" as compared to "active negotiators of change". There are good reasons for 'starting small' and building on success, particularly when the involvement of people with dementia is still a relatively new and evolving area of work. However, the processes by which involvement develops and power relationships change are complex and need active consideration and management by all concerned.

WHAT ARE THE KEY TASKS FOR MANAGERS?

- Provide strong leadership.
- Take steps to hear the many voices of people with dementia, reflecting the heterogeneity of the population of people with dementia.
- Be prepared to grapple with the very real ethical and practice challenges in involving people with dementia.
- Raise the priority of this work and ensure that there are designated resources to support implementation.
- Ensure the inclusion of people with dementia in mainstream involvement programmes.
- Ensure that there are arrangements to involve relatives of people with dementia in their own right.
- Harness existing staff expertise.
- Ensure appropriate support, training and development activities are available for people with dementia and for staff who want to develop their confidence and skills in involvement work.
- Ensure good practice leadership from specialist, expert dementia involvement worker(s).
- Ensure that the views of people with dementia obtained during consultation and involvement activities are taken seriously and that the people involved receive feedback about follow-up actions.
- Do not assume that the issues that services identify for consultation are important issues for the people with dementia. Ask them for their agendas.
- Encourage and support staff to try out new ideas in a context of ongoing learning through reflection and review.
- Encourage staff to share their learning widely to contribute to raising expectations and expertise in involvement work with people with dementia.

WHAT ARE THE KEY TASKS IN PRACTICE?

- Learn from the experience of the early innovators in dementia involvement work and from involvement work with other groups of service users.
- Provide explanations to people with dementia in a suitable manner with regular prompts and reminders throughout the process.
- Establish that each person with dementia consents throughout the process.
- Ensure that the environment, timing and other practical arrangements for meetings/events are suitable for the particular people with dementia involved.
- Include opportunities for small group discussions in any large meetings/events.
- Take account of people with dementia's needs for a gentle pace and straightforward language and use a range of communication tools and techniques, including non-verbal communication.
- Find out what support is wanted by people with dementia who are participating in formal meetings and ensure that it is available.
- Report back to all who take part in involvement activities in an accessible way to let them know what has happened as a result of their efforts.
- Value people with dementia's expertise and contribution, and recognise it through thanks and financial rewards where appropriate.
- Plan to enable people to move on to other activities when participation is no longer appropriate for them.

CONCLUSION

The involvement of people with dementia in service planning and development is in its infancy and there is much still much to learn. However, we now have clear demonstrations in practice that people with dementia are no longer prepared to be excluded and we have examples of the contributions that they can make. The task now is to build on these early successes, to encourage further learning from experience and to ensure that this learning is shared.

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PREFACE

INTRODUCTION

People with dementia have hitherto been largely 'left out' of the movement to ensure that users of health and social services are 'involved' in service planning and development. This guide aims to show policy makers, service planners and commissioners, service managers, and practitioners in health and social care, how much people with dementia have to contribute. It also aims to assist in developing the policies and practices that are needed to enable people with dementia to contribute as fully as possible.

This guide draws on a review of current literature on the involvement of people with dementia, and wider literature on user involvement, to provide an overview of what we know about involving people with dementia in service planning and development. We also draw on the practice experience of a range of involvement initiatives, which we describe in more detail below. However, involving people with dementia remains an innovative and evolving area of work. There are, therefore, many aspects of policy and practice about which we can provide good practice guidance, but few areas in which we can give definitive, evidence-based advice.

IDENTIFYING AND DEVELOPING GOOD PRACTICE

This guide is a product of the 'Involve People with Dementia' Project (IPWDP), which was based in Dementia North and funded by the Department of Health from 2002 until 2005. The Project aimed to:

- identify established good practice examples and ideas;
- test out a number of new approaches to involving people with dementia;
- disseminate good practice ideas and promote their uptake.

The Project combined a review of literature and good practice initiatives nationally, with more detailed work in four case study sites.

The review of good practice initiatives nationally was undertaken through contact with a wide range of local, regional and national projects and groups. These were identified by literature and web based searches, and contacts with key organisations and researchers in the field. Information was variously gathered about these initiatives through visits to the projects or groups; involvement of the projects or groups in IPWDP workshop events; and, telephone, e-mail or written exchange of information and ideas. We had some personal contact with a total of 11 projects and groups, and less intensive contact with a further five.

The main projects and groups with which we had personal contact were based in, or more loosely associated with, a range of organisations:

- three in NHS Trusts;
- two in Alzheimer's Society local branches;
- one in the Alzheimer's Society national office;
- one in Alzheimer Scotland;
- four in Dementia Services Development Centres (DSDCs)/universities.

The four more detailed case studies in which we were involved took advantage of a unique opportunity to work in a developmental way with participants in a Dementia Services Collaborative (DSC), a large multi-agency service improvement programme working across the North, Yorkshire and North Lincolnshire region. For further information about the DSC see Appendix 2. The Project worked with the DSC to develop its objectives on involving people with dementia and their carers, and to support this work across all of the DSC's local teams. More specifically, the Project recruited four of the DSC local teams as case studies to work more intensively on developing ways of involving people with dementia in service planning and development.

The planning and implementation of the project were informed by the views and ideas of people with dementia, gathered by the project worker through her contact with individuals and groups of people with dementia in the case study sites and other involvement activities with which she had contact. A Reference Group also supported the project.

The case studies

With each of the case studies, the Project worker had a facilitative role in helping local staff and service users to develop specific involvement activities. None of the sites had prior experience of involving people with dementia in service planning and development and there were no dedicated user involvement co-ordinator posts within the participating dementia care services.

The nature of the involvement activity to be developed in each site was determined by local people. In each area the work was undertaken by a group of people from a variety of backgrounds, with the DSC local team manager providing overall management support. The main features of the work in the four case study sites are summarised in Table 1.

TABLE 1: THE CASE STUDY SITES

	Case study 1	Case study 2	Case study 3	Case study 4
Location of activity	Private households	Private households Day hospitals and day centre	Care homes Day centres Inpatient units	Community centre Memory clinic
Agencies involved	Social Services Department Alzheimer's Society local branch	NHS Mental Health Trust Alzheimer's Society local branches Social Services Department	Social Services Department NHS Mental Health Trust	NHS Mental Health Trust Alzheimer's Society local branch
Staff involved	Home care staff and managers Older People's Team leader Advocate	Alzheimer's Society outreach workers Dementia home care worker Nursing staff and managers Occupational therapist (OT)	Care home staff and managers Day centre staff and managers Social work students on placement Nursing staff	Nursing staff and a manager OT Counsellor
Approx. number of people with dementia involved	15	100	90	12
Level of involvement	Individual care and service operation	Individual care and service operation	Individual care and service operation	Individual care and service operation
Approach	Consultation about home care	Consultation about services and methods of involvement	Consultation about quality of life and services	Consultation about services
Activities/methods	Individual and group discussions; consultation event.	Individual and group discussions.	Questionnaires; individual interviews about service journeys; observation; and, individual and group discussions.	Group consultation events; and, individual interviews about service journeys.

The Project worked with all four case study sites for just over 18 months. During this time the Project worker visited each site regularly to provide information and advice and help people to reflect upon, and develop, the involvement approaches being tried. Visits included observing and participating in local activities as well as meetings with staff. In between visits, the Project worker maintained regular contact, by telephone and e-mail, with the local lead managers to check on progress and provide ongoing support and encouragement.

USING THIS GUIDE

This guide has four sections. Section One provides an overview of the context and challenges of involving people with dementia in service planning and development. Section Two discusses briefly the nature of involvement and describes a wide range of approaches that have been used in involving people with dementia in different service contexts and for different purposes. Section Three deals with the organisational, management and staffing issues that agencies need to address to provide a receptive and enabling context in which the involvement of people with dementia can happen. This section will be of interest to service commissioners and service provider managers who have responsibility for service planning or operational policymaking and implementation. It will also be relevant to generic or specialist involvement workers who have a management role. Section Four focuses more specifically on the practicalities of involving people with dementia and will be of particular interest to involvement workers and to practitioners and front-line managers, for example of teams or service units, who have a central role in engaging directly with, and supporting, people with dementia in a wide range of involvement activities. Two appendices provide additional reading and links to useful websites.

SECTION ONE: CONTEXT AND CHALLENGES

INTRODUCTION

This section provides background information about the nature of dementia and the policy and service context for involving people with dementia. It then discusses some of the particular challenges that must be addressed to achieve effective involvement of people with dementia in service planning and development.

PEOPLE WITH DEMENTIA

In the UK over 775,000 people are affected by dementia, about 18,000 of whom are aged under 65 years¹. Dementia is an age related clinical syndrome characterised by progressive deterioration in mental functioning accompanied by a decline in personal and social functioning. Dementia results from a range of brain diseases, and has no cure². Recently, however, progress has been made in diagnostic techniques and in the development of drug therapies that are effective in slowing progression in the earlier stages of some forms of dementia (for sources of further information about the use of these drugs see Appendix 2). These developments have resulted in the identification of growing numbers of people in the early stages of dementia. They, and many people living with more advanced dementia, are able when given the right opportunities, to convey their wishes and views in ways that can inform service planning and development.

Until recently, the domination of the biomedical understanding of dementia resulted in scant attention being paid to the psychosocial context of individuals' lives. However, our understanding of the interplay between the person with dementia and their social and psychological environment is growing. Ideas about a 'new culture of dementia care'³, providing a psychosocial environment in which the human worth and 'personhood' of each individual with dementia is maintained and enhanced, are increasingly accepted. Alongside this psychosocial approach, the social model of disability is being applied to understanding dementia care. This model shows us how the experiences of people with dementia and their caregivers are adversely affected by the disabling and disempowering aspects of the social and service environment^{4,5}.

Previously it was widely thought that people with dementia were unable to express views about their situation or services. Practitioners and researchers tended to rely on proxy views, usually provided by family carers, rather than seek the views of people with dementia themselves. However, practitioners and researchers now recognise that carers' needs, experiences and perceptions of service provision can be very different from those of the person for whom they are caring.^{6,7,8,9,10} As our understanding of dementia develops, growing attention is being paid to how we can better 'hear the voice of the person with dementia', understand their experiences, views and wishes, and ensure that they can shape their own lives and the services that they receive.^{11,12,13,14,15} Work of this nature has shown that when people with dementia are helped to communicate, they have important things to say about how dementia affects them, and about what they consider important about their present and future lives, including how services should meet their health and social care needs.

Widening acceptance that people with dementia can, and should, have a greater voice is gradually having an impact on the way that services are organised and on the way that people with dementia are organising themselves. Example 1.1 illustrates the journeys of empowerment on which people with dementia are increasingly embarking.

THE POLICY CONTEXT

Choice, participation in decision making and involvement for service users are all central tenets of health and social care policies and enshrined in recent legislation, government initiatives and guidance.^{17,18,19,20,21,22} Although service user involvement is now well established as a mainstream issue in health and social care, there are still many problems to be addressed. For example, the Commission for Health Improvement (CHI)²³ notes:

"There are numerous champions of PPI [patient and public involvement] who are enthusiastic, dedicated, knowledgeable leaders at different levels of the NHS. But too often they are isolated and overwhelmed by the agenda and the number of operational and strategic tasks facing them. The work can be lonely,

EXAMPLE 1.1: JOURNEYS OF EMPOWERMENT

A journey in the UK

One person with dementia described to us the change they experienced when they joined a small, local social support group. In this non-threatening setting their confidence was nurtured and they gradually gained a sense of empowerment and of how they could speak out and contribute on behalf of people with dementia. They went on to become an active committee member of the Scottish Dementia Working Group (see p20 and p56). One of their aspirations is to see more local groups for people diagnosed with dementia, so that other people also can embark upon a process of empowerment.

An international journey

Christine Bryden, an early member of Dementia Advocacy and Support Network International (DASNI), was the first person with dementia to speak at the annual Alzheimer's Disease International (ADI) conference, giving the opening plenary address in Christchurch, New Zealand in 2001. In 2003 she was elected to ADI's Executive Committee.

She has written two books (see Appendix 1) eloquently describing her experiences of diagnosis and living with dementia. She describes how some people have found it difficult to accept her speaking out about living with dementia, but also how others have commented on the importance of her contribution, and that of DASNI more generally, in changing attitudes towards people with dementia. The following extract from her second book summarises her vision of a new relationship between people with dementia and 'families, friends, professionals and governments':

"We need to move...towards becoming a care-partnership, in which we accept, collaborate and adapt to new roles within the journey of dementia...I can communicate my true feelings, my true needs, so that you can walk alongside me adjusting and compensating for these expressed needs as we face this struggle together. In this care-partnership, the person with dementia is at the centre of the relationship, not alone as an object to be looked at, as merely a care recipient. Instead we become an active partner in a circle of care." (Bryden 2005, p150)¹⁶

take immense courage and require supportive networks." (CHI, p.3)

In the field of community care, the involvement of service users and carers in developing and assessing services is by no means new, although the extent to which involvement has been achieved varies in different services and different parts of the country. There has been substantial progress in establishing user involvement in disability services, in learning disability services and in working age adult mental health services, although many commentators point to the need for much more to be done.^{24,25,26,27,28} The involvement of older people as citizens and service users has also developed substantially.^{19,29,30} However, in practice frail older people are frequently under-represented in involvement activities and older people with dementia are generally notable by their absence.³⁰

Recently, however, there has been change. People with dementia have become more assertive in

speaking out about their experiences, their views, their wishes and their needs. We see this, for example, in the growing number of personal accounts of living with dementia that are appearing in books, journals and conference presentations (see Appendix 1); in the emergence of organisations like DASNI, the international internet-based support network run by and for people with dementia and their trusted supporters; and, in the small but growing number of peer support, self help and social groups of people with dementia in the UK who are making their voices heard in their local communities and service systems. We have also seen researchers increasingly giving people with dementia opportunities to express their views¹⁵, dementia care practice leaders exploring new ways of working with people with dementia to give them a greater say in the decisions that affect their lives and voluntary organisations, including the Alzheimer's Society and Alzheimer Scotland, undertaking a number of initiatives to give people with dementia a greater voice (see Appendix 2).

THE CHALLENGE OF INVOLVING PEOPLE WITH DEMENTIA

The challenge of involving people with dementia is in essence the challenge of addressing the social exclusion by which people with dementia:

“... are disempowered in a variety of ways. They have limited choice and control over their lives, they may have difficulty participating in the decisions that affect their lives and ultimately their fundamental rights as citizens and human beings may be infringed.” (Cantley and Bowes, 2004, p 256)³¹

Much of the work that has been undertaken in involving people with dementia to date has been undertaken by committed staff who have often worked against a prevailing culture of ‘non involvement’. Their work has remained small scale and often unrecognised because of the low priority it is given; the limited commitment and practical support available from peers and managers; heavy co-existing workload demands; lack of influence; and, lack of experience in organisational change management.

This guide deals with how managers and practitioners in health and social care organisations can support and work with people with dementia to involve them as fully as possible in planning and developing services. Such consultation and involvement of people with dementia can return some autonomy and control to them and contribute to their social inclusion.³²

This guide is concerned with ensuring that people with dementia, individually and collectively, have opportunities to express views and influence service planning and development. It is not primarily a guide to achieving person-centred care on an individual basis. However, it is important to acknowledge that this distinction is in many ways an artificial one since:

“The most significant forms of involvement are those that become part of the day-to-day practice of [service] delivery and planning, whether at the level of the individual encounter or at a more collective level.” (Ridley and Jones, p7)³³

The extent to which services are still falling short of achieving truly person-centred dementia care practice should not be underestimated and there are many other sources of guidance available to assist practitioners and manager with care practice development (see Appendix 2).

The challenges that managers and practitioners face in involving people with dementia in service planning and development are considerable. They include:

- Overcoming the deeply seated assumptions and prejudices that underpin widespread attitudes

that with people with dementia ‘it can’t be done’ or that ‘there is no point in trying’.

- Recognising that the service personnel who are in the closest relationships with people with dementia, and hence well placed to assist in engaging them in involvement activities, are often poorly trained, low paid and themselves marginalised in organisational planning and development.
- Recognising and taking into account that there are many voices of people with dementia, reflecting diversity in their gender, age, sexuality, ethnicity, social and cultural backgrounds, and abilities to understand issues, make decisions and speak out.
- Taking on board the very real ethical and practice issues entailed in hearing the voice of people with dementia and the extent of the time, skills and commitment that this requires.
- Overcoming negative organisational cultures in which dementia services, their staff and users, are viewed as low priority and as marginal to the central concerns of the organisation.

Some of the challenges of involving people with dementia are specifically related to the nature of dementia and the social exclusion associated with it. However, many of the challenges are shared in common with other user groups. For example, the challenge of ensuring that involvement is truly empowering of service users and not subverted by professional or managerial interests, and the challenges of changing services based on users’ views.

Overall, practitioners and managers embarking on dementia involvement work need to do so in full recognition that:

“User involvement is not a bolt-on extra. It is a way of changing the philosophy of an organisation and all the roles within it.” (NCCSDO, p1)³⁴

The involvement of people with dementia has lagged behind the development of involvement work with other groups. This is no longer acceptable, and change requires:

- leadership and senior management commitment to raising the priority of this work;
- designated resources to support implementation;
- a strategic approach to inclusion of people with dementia in mainstream involvement programmes;
- willingness to support innovation in areas where there is limited prior experience and established ways of working;
- fundamental shifts in attitudes and relationships with people with dementia.

SECTION TWO: WHAT 'INVOLVEMENT' INVOLVES

INTRODUCTION

The concepts and issues of user involvement have been well reviewed and discussed elsewhere (see Appendix 1). This section highlights key dimensions of involvement work with people with dementia and describes a range of approaches in practice.

WHAT WE MEAN BY 'INVOLVEMENT'

It is useful to think about five, inter-related, dimensions of involvement:

- values and principles;
- purposes and aims;
- models;
- organisational level;
- activities and methods.

Values and principles

The values that should underpin involvement work with people with dementia include:³¹

- Valuing personhood based on a holistic appreciation of, and respect for, the emotional, social, spiritual and artistic dimensions of the individual rather than a narrow focus on their cognitive abilities.
- Valuing 'relationship' with people with dementia and recognising the importance of interdependence and reciprocity.
- Valuing citizenship and having a commitment to social inclusion based on securing people's rights, promoting ordinary living and ensuring that people are empowered and have as much choice and control as possible.

In addition involvement work should be underpinned by the principles of ethical practice including those of informed consent, confidentiality and ensuring no adverse consequences for the individuals involved.

Purposes and aims

The aims of involvement for people with dementia can include some or all of the following:

- enabling people to play a full part in individual decisions about everyday matters and about major life decisions affecting their lives;

- enabling people to participate in the operation and management of services, for example in decisions about the selection of staff;
- enabling people to influence improvements and changes in the operation of services, for example influencing changes in the way in which referrals are made to specialist services;
- enabling people to influence future service provision, for example, influencing service planning to include the introduction of alternatives to traditional day care services;
- enabling people with dementia to have a voice in the policy making process, for example, in campaigning for new resources that will improve their quality of life;
- enabling people to have a voice in the wider communities of which they are a part, for example, in changing attitudes to dementia through their involvement in community groups.

In addition, involvement can have personal benefits for people with dementia who often report increased self-esteem and confidence arising from being included in involvement activities and feeling that they have something to contribute. As one person with dementia explained: "It's good to feel valued and to be a somebody not a nobody."^{35, p26}

Models

The classic model of involvement conceptualises it as a 'Ladder of Participation'³⁶ with steps ranging from non-participation through information and consultation, to partnership and ultimately citizen control. While this model, or some of its adaptations,³⁷ can provide a useful tool in practice (see p26), the notion of involvement as a linear process does not well reflect the complexity of approaches to involvement, and power relationships between service users and providers.³³

Another frequently used way of conceptualising involvement, draws the distinction between work that is 'consumerist' and work that is 'democratic'.^{28,33} The former, underpinned by notions of the service user as a customer with rights to information, choice and access, emphasises consulting people about the

services that they receive. The latter, underpinned by people's rights as citizens to access services and to contribute to the society of which they are part, emphasises much broader participation in decision making. Both models can be appropriate in different circumstances and for different purposes, although overall:

"...there has been a move away from the idea of just consulting people about agency-led proposals to the notion of developing services in active partnership with those who use them." (Carr 2004, p5)²⁸

We have already noted that people with dementia are a particularly marginalized and disempowered group of service users. The issue of power differentials between service users and providers is one that has been well recognised in the involvement field, for example:

"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." (Carr 2004, p vii)²⁸

Many existing dementia involvement initiatives have been service initiated with people with dementia being involved more as "passive suppliers of opinion" as compared to "active negotiators of change".³⁸ Sometimes, but by no means always, these involvement initiatives have been established by staff and managers on the assumption that service users will acquire greater power and control as they gain in experience and confidence, and as practitioners and managers increasingly recognise the value of their contribution. There are good reasons for 'starting small' and building on success, particularly when the involvement of people with dementia is still a relatively new and evolving area of work. However, the processes by which involvement develops and power relationships change are complex and need active consideration and management by all concerned.

Organisational level

Users of services can be involved at a number of organisational levels including:

- individual case level, for example, involvement in decisions that affect their own personal care or treatment;
- service level, for example, making views known about preferred activities in a day centre or about the information provided by a memory clinic;
- agency level, for example, influencing how the process of diagnosis is handled by psychiatrists in a NHS Trust;
- area level, for example, by contributing to locality-based, multi-agency consultation events and sitting on local planning groups;
- national level, for example, by being involved in projects with national relevance and contributing to working groups of national organisations, including voluntary organisations campaigning for better services on behalf of, or in conjunction with, people who have dementia and their carers;
- international level, for example, by participating in organisations such as DASNI and ADI and by making presentations at international conferences.

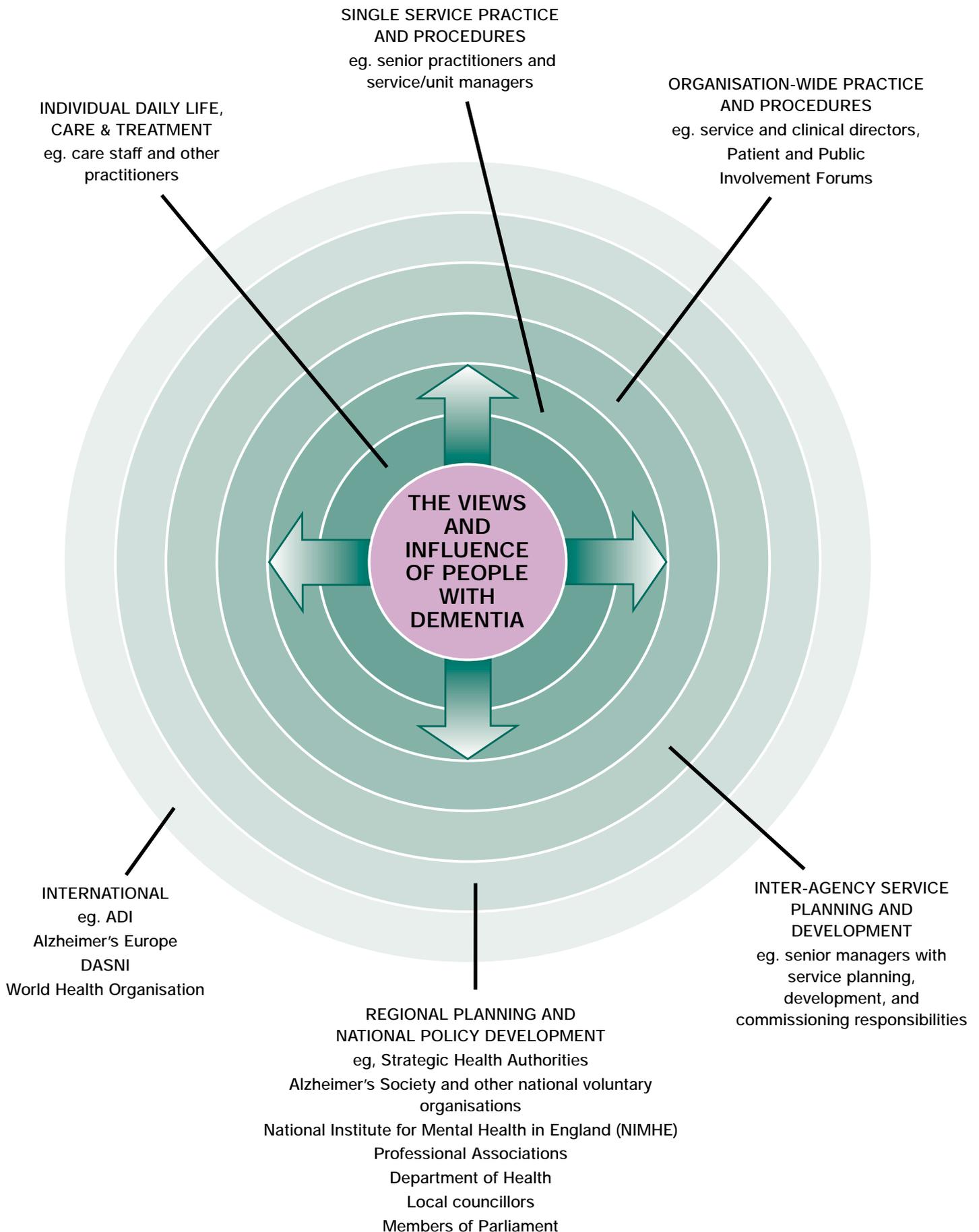
Figure 2.1 illustrates how the views and influence of people with dementia can impact in different ways, at different levels and on different organisational stakeholders. Sometimes an involvement activity may have an impact at more than one organisational level or across several organisations (see Example 2.1).

The majority of involvement activities with people with dementia are currently happening either in relation to the daily lives, care and treatment of individuals or in relation to single service practice and procedures. However, we are beginning to see examples of people with dementia having influence at every level and with a wide range of service stakeholders.

Activities and methods

Some involvement work employs specific research methods such as questionnaires or focus groups, but much work is undertaken through social interactions, events and activities that do not rely on specific techniques.³³ Whether or not research techniques are directly used, some understanding of research methods, particularly research related to understanding the perspectives of people with dementia, can be useful. For, while the requirements of research and of information gathering in involvement work are different, an appreciation of research perspectives can assist involvement

FIGURE 2.1: LEVELS OF INFLUENCE AND SERVICE STAKEHOLDERS



EXAMPLE 2.1: IMPACT AT DIFFERENT ORGANISATIONAL LEVELS

Staff in a NHS day unit set up a monthly group meeting to give people attending the unit more opportunities to discuss the issues that were important to them and to have their views heard by service providers.

People with memory difficulties expressed views about their experiences of the day unit's services and about wider issues. They raised a number of service specific issues including: wishing to see consultants more frequently; wanting a visit to the unit prior to attending to see if they liked it; and, wanting information from consultants provided in written form because of the difficulty they experienced in remembering information provided verbally. They also raised broader issues including: wanting more police on the streets to allay their fears of crime; wanting more choice in day facilities; and, wanting more information and advice about benefits.

Staff responded to the views expressed by: changing the way consultants provided information; contacting the local Police force about the provision of crime prevention advice; and, contacting their local Age Concern about provision of benefits information and advice.

workers in thinking about whether the information they collect is 'fit for purpose'. In particular, research perspectives show how involvement workers can assess the information they have collected in terms of: how it may be influenced by the method of collection or by the people who are collecting it; whether it represents the views of a broad population of people with dementia or more minority interests; the extent to which the people involved would feel the information reflects what they want to say; and, the extent to which the information can be applied across different settings or times. The research literature can also provide involvement workers with advice on the principles and practice of specific methods, as well as guidance on using them in working with people with dementia (see Appendix 1).

It is important to recognise that some involvement activities are more self-evidently empowering than others, for example self-advocacy groups as compared with satisfaction surveys. However, sometimes the implementation process can be a significant consideration. Thus, for example, a survey of service user views that is commissioned from a group of service users who have full control and decision making powers throughout the work, is very different from a survey that is designed, distributed and analysed by an organisation without any direct negotiations with service users.

APPROACHES TO INVOLVING PEOPLE WITH DEMENTIA

A range of approaches have been used, to varying extents, in the involvement of people with dementia. We describe four categories of approach: individual consultation, group consultation, participation, and

collective action. Each of these approaches can be pursued using a range of activities or methods. The appropriateness of a particular approach, and specific activities and methods, needs to be considered in relation to the abilities and characteristics of the people with dementia who will be involved and the aims and purposes of the involvement. All of these approaches, and a wide range of activities and methods, may be used with people who are living with the earlier stages of dementia. Whilst, for people with more advanced dementia, individual approaches with activities that take place in familiar settings and greater opportunity for non-verbal expression, are generally more suitable.

Individual consultation

First, this type of approach entails a number of individuals being given opportunities to separately express their views with staff subsequently collating the information obtained to feed it into service planning and development processes. The methods that can be used include:

- consulting in the course of service provision;
- questionnaires;
- personal or telephone interviews;
- observation.

Some illustrations of this type of approach are provided in Example 2.2, and further examples and guidance on the application of this type of approach are included in Appendix 1.

Group consultation

Second, in this type of approach people with dementia come together with staff to share, discuss

EXAMPLE 2.2: INDIVIDUAL CONSULTATION

Consulting in the course of service provision

A number of the IPWDP sites adopted the approach of staff asking people with dementia for their views during service encounters, for example whilst they were attending a therapeutic group or during day-to-day contact with a resident in a care home. They found that this type of involvement approach could be highly tailored to individual abilities and preferences. However, it could be difficult for staff to manage the dual focus of care and consultation without one or other, or both, activities being compromised. It could also be difficult practically for staff to record the views that people expressed.

Using a questionnaire

Staff in care homes used a questionnaire to seek the views of residents with whom they worked closely. The semi-structured questionnaire, which contained four questions (related to meals, residents' rooms, activities and staff) was designed by two care home managers. Staff were briefed about how to complete the questionnaire in conversation with each resident and in a context that would help prompt their responses (for example, asking questions about food in the dining room). Staff drew upon their knowledge of each resident to decide when, where and how they would complete the questionnaire. Where necessary, they recorded residents' responses after their interaction with them had ended, so that residents did not feel that they were under pressure to give 'right answers'. Staff were asked to record their observations of the person's non-verbal responses as well as their comments. Some staff were reluctant to take part because they thought it impossible to elicit the residents' views or were anxious about doing 'paperwork'. However, the exercise was eventually completed and residents' responses used to inform an action plan for the homes. While some staff remained unconvinced that the questionnaire approach added to what they knew from their day-to-day contact with residents and from the home's monthly Residents' Meetings, they did see benefits, as one staff member explained:

"It seemed that for the residents it was beneficial to them because they seemed... I don't know. Would it seem a cliché if I said I felt it made them feel important? That one-to-one...with a [questionnaire]..."

Using interviews

Staff within an in-patient assessment unit for people with dementia tape recorded interviews in which people with dementia were asked to 'tell their story' about their journey into and through the service. People expressed concerns that included: lack of information and pre-planning for admission; unnecessary delays in their discharge; limited opportunity for escorted home visits; fears about the security of their homes; lack of information regarding their memory problems; and, not being told their diagnosis. From the process staff gained a new understanding of the experiences of people with dementia and there was a resolve to address the issues raised.

Using observation

Since observations are very much open to the subjective interpretation of those undertaking them, and since observation implies a passive role for the person being observed, there are obvious limitations in using observation as a method of involvement. However, if the observer is able to adopt the role of independent advocate, trying to discern and represent the views and wishes of the person with dementia rather their 'best interests', then observation has the potential to make a valuable contribution particularly as a means to including the perspectives of people with more advanced dementia. One example of this type of observation in practice involved social work students on placement observing aspects of life in a day care centre. The students were able, for example, to represent the views and wishes of people with dementia for changes in mealtime arrangements, based on their observations of the way people with dementia had been responding to staff, other residents and the environment in the dining room.

and express their views for staff to record and convey into planning and development processes.

The activities include:

- consultation in the course of service provision;
- discussion groups or forums set up specifically for involvement purposes;
- seeking views from members of pre-existing social or support groups.

Some illustrations of this type of approach are provided in Example 2.3.

Participation

Third, in this type of approach people with dementia, either individually or in small groups, participate directly in service planning and development processes. The activities include:

- meetings with senior managers and other decision makers;
- membership of formal planning groups and committees;
- involvement in service management such as audit and evaluation or staff selection;
- involvement in staff training and development.

Example 2.4 provides illustrations of this type of approach in practice.

Collective action

Fourth, in this type of approach people with dementia are themselves in control in acting collectively to influence services and the broader communities of which they are part. Often involvement activities of this kind are combined with elements of peer support. Some illustrations are provided in Example 2.5. There is the potential for this type of activity to evolve into a 'user movement', as has developed for other groups of people with disabilities. It is as yet too early to tell whether this will happen.

Learning from others

The approaches that we describe above, and other involvement methods and activities, have been further developed and applied in involvement work with other groups of service users. Based on this experience a number of guides have been produced on using different approaches for different involvement purposes (see Appendix 1). Although not specific to dementia services, these guides can nonetheless provide practitioners and managers with ideas that might be adapted for use in dementia involvement work.

KEY POINTS ABOUT DEMENTIA INVOLVEMENT

- The involvement of people with dementia should be founded on values of personhood, relationship and citizenship and on the principles of ethical practice.
- The purposes or aims of involving people with dementia range from influencing the operation of individual services to influencing social attitudes nationally and internationally.
- Involvement can have personal benefits for people with dementia who often report increased self-esteem and confidence arising from being included in involvement activities and feeling that they have something to contribute.
- Involvement activities with people with dementia can take place at a range of organisational levels, with the stakeholders to be influenced ranging from practitioners to policy makers.
- Approaches to involving people with dementia include individual consultation, group consultation, participation and collective action. With each of these approaches a number of activities or methods may be used.
- It is important to recognise that some involvement activities are more empowering of people with dementia than others.
- Many existing dementia involvement initiatives have been service initiated with people with dementia being involved more as "passive suppliers of opinion" as compared to "active negotiators of change". There are good reasons for 'starting small' and building on success, particularly when the involvement of people with dementia is still a relatively new and evolving area of work. However, the processes by which involvement develops and power relationships change are complex and need active consideration and management by all concerned.
- The majority of involvement activities with people with dementia are currently happening either in relation to the daily lives, care and treatment of individuals or in relation to single service practice and procedures. However, we are beginning to see examples of people with dementia having influence at every level and with a wide range of service stakeholders.

EXAMPLE 2.3: GROUP CONSULTATION

Consultation in the course of service provision

A voluntary organisation in one IPWDP site used this approach in day care as a member of staff explained:

"I think we approach user involvement differently to other areas. We maybe don't do it so formally. We do it by listening to the groups, during lunch or whatever... So we don't really sit down and say, 'What would everyone like to do, because you don't get a direct answer because no one wants to say, "This is what we want to do." We try and listen to the conversations, ask all the workers involved what they think we should be doing, and go out and try it. If it is successful we know we've done the right thing. If it is not successful then that's also telling us it's not the right thing they want. So we try and learn from those sorts of things. It is not really a formal way of approaching it and I don't know if that is right or not..."

Focus groups

In one NHS Trust, users of the older people's mental health services were invited to join focus groups. Separate groups were held for people with dementia and people with functional mental health needs. Each focus group had four participants and lasted approximately 30–45 minutes. Preparatory pre-group visits were not undertaken, although with hindsight the organisers thought that it would have helped to have done this. The discussions were tape recorded and an observer took notes which proved to be valuable because participants' speech was not always loud enough, or clear enough, to be reproduced from tape recordings alone.

The facilitators opened the discussion with general conversation starters and allowed the discussion to develop as participants wanted. People with dementia talked openly about their 'memory impairment' and what it meant to them. Their comments about wanting 'family time' at weekends rather than day care were particularly interesting as this was different from the views of other service users and from the assumptions underpinning the service.

A consultation event

A consultation event was organised by a local Alzheimer's Society branch. Participants included three people with dementia. Speakers from statutory sector services made presentations prior to roundtable consultation exercises. The people with dementia commented that too much information on the slides meant that the presentations were "too much to take in" and that it was "best just to listen". Their views about the consultation activity were more positive. They described being "comfortable talking in circles". Their contributions included praise for an advocacy service whose worker made one participant "feel better", and criticism of the home care service by another participant for buying food for her that she did not like.

Setting up a discussion forum

One IPWDP site established a new forum so that people with dementia and their carers could share their experiences to inform service planning and development. Initially, the forum was going to be time-limited to three 'mini consultation events' but due to the success of the meetings, it became an established monthly event.

Using an ongoing social support group

One group for younger people with dementia and their supporters was set up by an occupational therapist working with staff from the local Alzheimer's Society's branch. The group's aim of influencing service planning, development and delivery was agreed with group members. Staff prepared very carefully for the group and in order to avoid it becoming service dominated, group members were encouraged to express what they felt they wanted from it. It soon became apparent that the people with dementia and their supporters felt that they could not talk freely and frankly in each other's presence. So, at the request of group members, separate rooms were arranged for the group to split after meeting for an initial drink and a chat. The views and opinions expressed by group participants were used to shape their individual care and treatment plans and also, through staff membership of a multi-agency older people's service development group, to influence wider service planning and development.

EXAMPLE 2.4: PARTICIPATION

Involvement in service evaluation

Facilitators of a support group, who wanted to involve people with dementia in evaluating the group, devised word/picture cards as a visual prompt to assist group members in expressing their views. They designed small 'Feelings Cards', showing hand drawn facial expressions with the corresponding emotion written underneath (e.g. enthusiastic, proud, happy, curious). The cards were subsequently amended to include colours to reflect emotions. The two facilitators, an occupational therapist and a nursing assistant, regularly confirmed with group members that they were willing for their comments/views to be passed on to inform service development.

Meetings with senior managers

One project manager invited the local Primary Care Trust's lead manager for patient and public involvement to spend a morning at a Memory Clinic, to meet with staff and informally with service users. One person with dementia and their partner had agreed to meet the manager to share some of their experiences of services and of being involved in a series of small consultation events. The meeting went very well from everyone's point of view.

The success of this informal encounter brought home to the project manager just how much impact meeting and talking with people with dementia could have on senior managers. As the clinic already held regular consultation meetings with people with dementia and their relatives, staff asked the group for permission to invite senior management 'visitors' to one of the meetings.

The invitation to senior managers asking them to "drop in" was informal to ensure that any visits would be low-key and non-threatening for all concerned. A clinical services manager and an older peoples' services manager called in to a subsequent meeting and talked a little about their roles and responsibilities. As an outcome of these discussions, the two managers offered to come back for further discussion about how people experienced services and what they wanted from them.

The project manager described witnessing the interactions between these key decision makers and the people with dementia as being a bit like a "religious encounter". For her it felt as if a very important step had been taken towards people with dementia having a much more collaborative relationship with influential service decision makers.

Influencing a national organisation

The Alzheimer's Society's Living with Dementia Project was set up in 2000 to involve people with dementia more directly in the organisation. The project has enabled people with dementia to be more actively involved in a range of the Society's activities. For example, people with dementia have been involved in writing and designing an information booklet for other people with dementia, in speaking at conferences, in giving media interviews, in writing for newsletters, in fund raising, in recruiting new staff and in attending local and national meetings to express views and vote on issues. When the Society hosted a conference at the Café Royal in London to celebrate and give thanks to the people with dementia who had taken part in a range of consultation and involvement activities, over sixty people with dementia and forty carers attended. A range of the Society's staff and Trustees were invited to take part in the day which was chaired by a person with dementia and included a presentation by a person with dementia.

EXAMPLE 2.5: COLLECTIVE ACTION

The People Relying on People Group (PROP)

In 1999, a new NHS post was established, in Doncaster, with the remit to develop services that would be responsive to the views and needs of younger people with dementia and their supporters. The worker who was appointed encouraged service users and carers to set up a group that would inform service development. This resulted in the PROP Group, an independent group that is self-managed by a committee and in which the role of vice chairperson has been held by a person with dementia. The Group has a written constitution (important in obtaining funding) but meetings are conducted informally to enable full participation for all members. The Group has had an impact in a range of ways: in influencing local practice in areas such as care planning; in being involved in the selection of service staff; in giving presentations to service commissioners and managers about the experience of living with dementia and using services; in having representation in local service planning meetings; and, in campaigning for ongoing funding to support the early onset dementia service.

Scottish Dementia Working Group

This is an independent group, formally constituted within Alzheimer Scotland, run by people with dementia with the support of a co-ordinator. The group is funded by Comic Relief and Alzheimer Scotland. The group campaigns to improve services for people with dementia and improve attitudes towards people with dementia.

This Group was established following an invitation to people with dementia being widely circulated by one person with dementia. He was convinced that people with dementia in Scotland needed a voice to question and influence services and government and to improve public perceptions of dementia. The existence of members who are willing to lead and chair the Group has been a significant factor in its success, as has been the support of Alzheimer Scotland. Members have been involved in speaking at conferences and in giving interviews to the media, in commenting on policy consultations and in producing a range of information and publications for other people who have dementia.

Dementia Advocacy and Support Network International (DASNI)

This is a not-for-profit, internet-based, and member run organisation. Its membership is international including people with dementia in the UK, Canada, USA, Australia, New Zealand and Brazil. DASNI states its Principles, Beliefs and Values as follows:

- “● We are autonomous and competent people diagnosed with dementia, and our loyal allies
- We believe that shared knowledge is empowerment
- We believe our strengths provide a supportive network
- We are a voice and a helping hand
- Our purpose is to promote respect and dignity for persons with dementia, provide a forum for the exchange of information, encourage support mechanisms such as local groups, counselling, and Internet linkages, and to advocate for services”.

SECTION THREE: MANAGEMENT MATTERS

INTRODUCTION

Section One noted that there is much resistance to the idea of involving people with dementia. Managers therefore have a two-fold role: first, they need to make sure that any embryonic involvement work is identified and supported to develop constructively; and, second, they need to proactively promote new involvement initiatives and an organisational culture that accepts and expects people with dementia to be involved in a variety of ways.

This section discusses the issues to be considered and addressed by managers at a range of organisational levels, in statutory and voluntary sector organisations, who have responsibility for the involvement of people with dementia in service planning and development. It provides guidance on organisational arrangements, on processes, and on staffing and resource needs.

VALUES AND PRINCIPLES

In Section Two, we suggested some values and principles that should underpin involvement work with people with dementia. If an organisation is to support the involvement of people with dementia effectively, managers need to ensure that their organisation has a sound value base for the work. Their aim must be for ownership and commitment throughout the organisation, from the chief executive to front-line practitioners and support service staff.

Prior to any involvement activity, it is important that managers take into account that, in many areas of dementia care, there will be a need for considerable preparatory work on 'changing the culture'³ to promote these values and principles and persuade staff that people with dementia can, and should, be given more say. Managers may find that staff who are working to give people with dementia a voice in the organisation, have to overcome prejudiced assumptions about people with dementia and resistance related to the low status and priority that is frequently accorded dementia services and those who work in them.^{3, 31} For example, in some areas care staff have reported that their attempts to convey the views of people with dementia have been

disregarded and not respected by more senior staff. This disempowerment of staff in many ways mirrors the experiences of people who have dementia.

ORIGINS

The initiative for people with dementia to be involved in service planning and development may come from a range of sources. Ideally, the source would be a person with dementia or a group of people with dementia who want to have a greater influence, or members of a broader community group, perhaps of older people, who want to encompass the voice of people with dementia within their campaigning activity.

In reality, for a variety of reasons including the particular problems faced by people with dementia and the social exclusion of people with dementia that we discussed above, the initiative is likely to come from within a statutory or voluntary sector organisation, for example, from:

- a health or social services practitioner who wants to ensure that the type of care packages available are shaped by the views and preferences of people with dementia;
- a manager of health or social care services who is charged with developing services for people with dementia;
- a commissioner of services for people with dementia who is seeking involvement to inform purchasing decisions, service level agreements or local targets;
- an inter-agency planning group seeking to ensure that people with dementia have as much opportunity for involvement as other service users for whom they are responsible;
- a Patient and Public Involvement (PPI) manager who has been convinced of the need to include people with dementia.

When involvement is being promoted by managers or staff, it is essential that people with dementia are engaged as active participants in shaping the work from as early as possible and at all stages along the way.

ORGANISATIONAL ARRANGEMENTS

The organisational location for an involvement activity will depend upon the level of the activity, its purpose and where those involved want power and control to be located (see Section Two). These factors are in turn likely to be influenced by the origins of the involvement initiative.

Dementia involvement activities may be located in voluntary organisations, such as the Alzheimer's Society local branches, or may be undertaken by groups of people with dementia and their supporters (who may be family members, friends or sympathetic service practitioners) that operate independently or with a loose affiliation to a voluntary or statutory agency. This model has most potential to empower people with dementia and give them autonomy in determining the issues in which they want to be involved with service providers. The management challenges for the organisations to which such activities are affiliated, are to provide as much support as necessary and to offer guidance on how to maximise the impact of involvement activities, while avoiding the risk of controlling or taking over what is often a fairly loose and fragile edifice.

Dementia involvement activities may also be located in statutory sector service organisations. Often the managers involved will have responsibilities that extend beyond dementia care, for example to include all older people's services or older people's mental health services. This can raise the question of whether the involvement initiative should be dementia specific or whether people with dementia should be included in broader involvement activities. While it is extremely important that dementia involvement is included in agency-wide involvement work, experience suggests that, at the level of practice, it is often necessary to provide specific opportunities for people with dementia to contribute.

Another question that managers often raise is whether it is better to have the activity led by an internal involvement worker or an external facilitator. Each approach has its merits. From the experience of the IPWDP sites, the independence of an external facilitator from management structures and local politics can make it easier for them to raise difficult issues, challenge existing practice, elicit staff concerns, avoid role confusion between involvement activities and other roles in the organisation and, bring additional knowledge and experience from outside the organisation. Internal workers on the other hand may be able to capitalise on familiarity with the organisation's structure, operation and

politics, on having existing networks and relationships and on having position power in dealing with management issues such as staff workload priorities.

Some dementia involvement initiatives are inter-agency, and this may raise the question of which organisation is best placed to host and lead the work. One of the likely points of discussion will be whether dementia involvement activity is better located within an organisation that specialises in dementia care or issues, but has limited expertise in user involvement work, or better within a generic user involvement organisation where there may be limited expertise in working with people with dementia. Factors to be considered include which organisation will best provide: a familiar and comfortable physical and social environment for people with dementia to meet and discuss their views; expertise in communicating and engaging with people with dementia; the skilled facilitation and support that people with dementia will need to become involved effectively; the independence that will enable people with dementia to feel uninhibited in expressing their views; credibility and effectiveness in working with the people and organisations to be influenced; and, acceptability to the family members whose support will be important. The relative importance of these factors will vary with the nature of the proposed activity.

RESOURCES

Involving people with dementia should not be regarded as a "project" or one-off activity. If involvement is to be effective it must be thought of as an ongoing and evolving process that becomes embedded in the organisation's culture and day-to-day practice. Without such commitment, the involvement of people with dementia will simply become yet another precarious activity with the potential for generating scepticism and achieving no more than tokenism.

Since dementia services in general, and dementia involvement in particular, have generally been marginalised and a low priority for resources, managers in health and social services organisations need to consider how this situation can be redressed. For if the necessary resources are not made available to support involvement work, staff interest and initiatives will struggle to survive. One of the major areas for investment is likely to be the appointment of a dedicated dementia involvement worker/facilitator. This role is discussed in more detail below.

For multi-agency dementia involvement activities, the possibility of pooling resources across participating agencies should be explored. This can have the added advantage of generating a greater degree of commitment and mutual ownership of the work and its outcomes than might otherwise be the case.

For involvement initiatives that are not located in mainstream health and social services agencies, it is often necessary to search out funding, and other resources in kind, from a range of statutory and charitable sources. Informally constituted involvement groups generally find that in order to secure resources, they either have to establish themselves as a registered charity or develop an affiliation with another organisation through which funds can be routed and managed. Whatever the source of the funding, or support in kind, it is important that the funder, or supporting organisation, respects the 'independence' of the involvement group/organisation and the need for its participants to be able to express their views freely and without fear of withdrawal of support. This should be made explicit in any funding agreements or terms of reference agreed with the group/organisation. Some information about sources of advice for voluntary groups and organisations is provided in Appendix 2.

ESTABLISHING THE BASELINE

One of the first steps for managers who are considering how to set up or support involvement initiatives, is to review the involvement of people with dementia that is already taking place in their own and other organisations locally. Such a review, which should identify examples of good practice and expertise in the field, as well as gaps in involvement activity, can provide a basis for ensuring that any new initiatives do not lead to duplication in work for staff or people with dementia.

Establishing the baseline of local involvement activity is likely to require a range of enquiries as people with dementia may be encompassed in more generic user involvement activities, or may be involved in work taking place outside formal 'user involvement' programmes. Fruitful routes of enquiry might include:

- staff with lead roles for developing dementia care services;
- interagency planning groups, for example, Local Implementation Teams for the National Service Framework for Older People²⁰;
- corporate departments concerned, for example,

with audit, performance management, comments and complaints, public information;

- community or voluntary sector organisations such as the Alzheimer's Society;
- Patient and Public Involvement leads, community development workers and user involvement co-ordinators in local health care and social services organisations;
- existing consultative or involvement activities such as Resident's Meetings in care homes.

As well as gathering information about existing user involvement activity, a mapping exercise of this kind can identify potential support and prompt more staff to think about whether people with dementia are being involved and if not, why not. This can have a snowballing effect in generating more interest and support.

SUPPORT, INFLUENCE AND IMPACT

Some involvement activities develop in a 'top down' way in the context of an organisational involvement strategy. However, managers can also be more opportunistic in using external service reviews, inspections or evaluations to promote user involvement in dementia services. Internal reviews too can provide a good incentive for involvement work, for example a financial imperative to review a service that is functioning under capacity may provide an opportunity to involve service users in putting forward ideas about how resources could be reallocated to better meet their needs.

Managers seeking to introduce dementia involvement activities, need to remember that staff may have had little or no experience of this type of work. Even those staff who are supportive in principle may have doubts about the ability of people with dementia to contribute, or about their own ability to work in new ways. Such reluctance is often overcome once staff have had the experience of hearing and responding to the voices of people with dementia. Before launching ambitious dementia involvement programmes, it can therefore be useful for managers to give staff opportunities to hear people with dementia speak out, for example during staff training sessions, as well as opportunities to try out some small scale, and non-threatening, involvement activities. Preparatory activities of this kind can help overcome any staff reluctance and build their confidence in their own abilities to involve people with dementia constructively.

Some involvement initiatives develop in a ‘bottom-up’ way either from people with dementia and their supporters, or from front-line staff. If these initiatives are to be effective it is important the managers pick up on what is happening as early as possible to ensure that the work links with, and is supported by, the organisation’s broader user involvement strategies and resources. In particular, managers should ensure that there are training and development opportunities available for people with dementia and staff who want to develop their confidence and skills in involvement work. If the organisation has limited management expertise in dementia involvement, external sources of support and expertise might be used, for example from the Alzheimer’s Society (or Alzheimer Scotland), dementia services development centres or NIMHE Regional Development Centres (see Appendix 2).

In the field of dementia care, the engagement of relatives is likely to be particularly important, as without their support many people with dementia will find it difficult to participate. However, as we noted in Section One, it is easy for the voices of relatives or carers to drown out those of people with dementia themselves. Managers need therefore to ensure that the organisation’s approach to involvement engages family members’ support while avoiding family members’ views and perspectives becoming a proxy for those of people with dementia. This is likely to require that, in addition to involvement activities with people with dementia, there are separate opportunities for relatives to be involved as service users in their own right (this particularly, but not exclusively, applies to family carers).

Experience suggests that dementia involvement activities, particular those that are the initiative of front-line staff or junior managers, can sometimes be marginalised within the organisation. It is therefore important that managers ensure formal recognition of dementia involvement activities in organisational structures and systems appropriate to the nature and level of the activity. Managers should also consider the multi-agency dimensions of involvement work and ensure that their management colleagues in partner agencies are engaged and committed to supporting the process and responding to the outcomes.

Managers need to consider where and how dementia involvement activities will ‘feed in’ to ensure that the views of people with dementia have influence. It is well recognised that one of the biggest challenges for user involvement programmes in general, is to ensure that users’ views are taken seriously and have real influence, for example:

“The NHS seems to be getting better at finding out what matters to patients, carers and the public – less good at doing things about it. It is having a hard time shifting from ‘feedback’ mode (gathering information about the patient experience) to ‘influence’ mode (sharing a seat at the decision making table with patients, carers, service users and the public).” (CHI undated, p13)²³

Managers need to be alert to the possibility that themes and messages arising from consultation or involvement initiatives in one service setting may be applicable in other settings. Central reporting systems should therefore be in place to ensure that the feedback obtained from various consultation and involvement activities is collated and that there are arrangements to consider the follow-up action that should be taken, perhaps through quality assurance systems, developments in local policies or procedures, or multi-agency planning.

Consulting and involving people with dementia gives out a strong message of hope to people with dementia, their carers and families, and the large number staff working in this field, that at last their experiences are being recognised. Failure to translate into action the views and experiences gathered through involvement activity risks quashing the hopes, expectations and morale of people with dementia, their families and care providers. It is also a waste of expertise and already scarce resources. Managers developing dementia involvement activities need to address this issue from the outset:

“If we seek to involve people who have dementia [in evaluating the services that they receive] then we have a duty to ensure this information does make a difference to the future provision of services. If reliable structures are not in place to ensure their voice is heard and acted upon, then exercises such as these can be accused of amounting to no more than tokenism.” (Cheston et al. 2000, p478) ³⁹

THE APPROACH

The specific involvement activities to be undertaken need to be tailored very carefully to the circumstances of the service and the individuals with dementia who are participating. Detailed decisions about activities, and how they will be run, are primarily the province of the people with dementia, practitioners and involvement facilitators who will undertake the work. This is dealt with in more detail in Section Four.

The main task for managers is to provide a clear and supportive organisational context in which this detailed work can develop. This requires them to think about the degree of control and influence that people with dementia have within current user consultation and involvement activities and the type of involvement that they want to achieve. Questions to be considered include: How much influence do service users really have in deciding, for example, where and how to focus the consultation or involvement activity? How does this level of influence compare with that of professionals? To what extent are local involvement activities truly service user led and service user focused? Considering these questions can help managers clarify whether the degree of service user influence currently being achieved is justified or whether this should be increased in future involvement activity.

Managers need to think about purpose, organisational level and key stakeholders (see Section Two) and also the method, or methods, that are most appropriate. However, in doing this they should not lose sight of the fact that dementia involvement work is still in an embryonic state compared to involvement work in other fields. They need therefore to be prepared to set the broad direction of travel rather than detailed plans and targets. They also need to accept, and make clear to all involved, that the overall approach is to promote organisational learning, including learning from activities that do not always go as well as anticipated.

Ensuring that people with dementia have influence at different organisational levels is enormously important. There can be a tendency for staff undertaking involvement work to assume that the views and suggestions of people with dementia generated in one activity will somehow spread across the organisation or filter up or down to influence other levels of policy making and service management. Such spread and influence are only likely to happen if managers put in place systems to ensure that staff are proactive in informing and influencing their colleagues and managers. In any event such systems should best be regarded as a complement, not an alternative, to having more direct input from people with dementia at a variety of levels. This might be achieved by using a number of the approaches outlined in Section Two.

ETHICAL ISSUES

One aspect of involvement work with people with dementia that is distinctive, although by no means exclusive to working with people with dementia, is

the centrality of ethical issues. These issues include:

- ensuring that people understand the nature of the processes in which they are engaging;
- ensuring that people consent to participation;
- maintaining confidentiality and protection of individual identities in any reports or other actions arising from the involvement;
- ensuring that people can express their views freely without fear, or risk, of any adverse response from their service providers;
- dealing with any instances of abuse or unacceptable practice that come to light in the course of the involvement work.

For further discussion and guidance on ethical practice and the legal principles related to mental capacity see Section Four and Appendix 1. Managers should ensure that they have in place policies and procedures to address any issues that are likely to arise.

In some instances, NHS staff organising involvement activities with people with dementia have been required to submit an application for ethical approval by the Local Research Ethics Committee (LREC). Whether a particular involvement activity constitutes research or not, and hence requires LREC approval or approval under clinical governance procedures, is a matter of judgement and there is clearly some variation in local practices. The development of new social care research ethics arrangements may also have implications for involvement work with people with dementia. Managers therefore need to ensure that staff receive guidance on governance and ethical requirements prior to embarking on any involvement initiatives. More generally, managers need to ensure that staff who undertake involvement work with people with dementia receive training, support and supervision in relation to ethical practice. This may usefully include experienced practitioners providing role modelling and coaching, for example through co-facilitation of group work. For further information sources see Appendix 1.

STAFFING

The number and type of staff required for involvement work will vary depending on the nature of the involvement activity. For example, some setting specific activities may involve considerable numbers of front-line staff in seeking the views of people with dementia. One of the key challenges in promoting staff engagement in the involvement of

EXAMPLE 3.1: GETTING STARTED

A meeting between an external facilitator and newly established multi-agency Involvement Working Group decided on the focus for initial work. The involvement of younger people with dementia was identified as the preliminary target group because a service review had demonstrated major gaps in provision for this client group. Also, since there would be opportunities to involve younger people with all stages of dementia across a wide range of services, this focus would provide valuable lessons for subsequent involvement activities.

At the next meeting the facilitator introduced a range of ideas and examples about different types of involvement activities that have been found useful by people with dementia. She also used a tool based on the Ladder of Participation (see Section Two) to promote discussion about the nature of the involvement being planned. The multi-agency group then worked through a range of questions to help them progress their initial ideas and translate them into a project plan. Each question was written on a separate piece of flipchart paper and displayed on the walls around the room, giving everyone a chance to contribute their ideas and preventing any one person or agency dominating the planning process. The questions posed were as follows:

- Why do you want to involve people and what do you want to achieve?
- What levels of involvement are right for the task?
- Who would you want to consult/involve?
- Have younger people with dementia previously been consulted/ involved on the same, or similar, issues?
- What scope is there for younger people with dementia to make changes and influence decisions across local services?
- What will you do with the ideas and information that emerges? How will this information feed into the decision making process?
- Should you involve anyone else from voluntary or statutory services or the local community?
- How will the outcomes be fed back to the people who have been involved?
- What type of support and information are those involved likely to need? How can this be provided?
- How can you access younger people with dementia to invite them to participate?
- How can you capture the learning from the work?
- How will you know if the consultation/involvement was worthwhile?

For a subsequent meeting, the facilitator used the group's responses to these questions to produce a statement of their shared vision for involving younger people with dementia and a sketch of the baseline of involvement from which the group was setting off in pursuit of their vision. The facilitator encouraged the group to use this information as a basis for deriving their aims and short-term objectives to inform the development of a detailed action plan.

people with dementia is to raise their confidence in their own abilities and expertise:

“Good practitioners already have much of the knowledge and many of the skills needed to enhance communication and make consultation and involvement a reality. We need to find ways of helping staff to recognise and value these resources, and to use them in the most effective ways.” (Allan 2001, p44)¹³

Managers should be aware that the work entailed in involving people with dementia can be immensely rewarding for staff but also complex, challenging and emotionally draining. Experience has shown that it can be difficult to sustain staff motivation and momentum when involving people with dementia, particularly if staff have to struggle with other conflicting demands on their time.

Most dementia involvement projects have one, or perhaps two, key members of staff who have overall responsibility for the work and who serve as ‘champions’ for people with dementia to have influence in the service system. Dementia involvement activities are more likely to be established and sustained when there is an appointment of a dedicated involvement worker. In practice such posts are likely to be held by senior practitioners or first-line managers on a part-time basis. Whether a post is full-time or part-time, it is important that the role, responsibilities, boundaries and lines of accountability are clear and that the post is senior enough to guarantee sufficient positional power and strategic influence to be able to make an impact. This clarity and seniority is especially important for multi-agency involvement work. In order to operate effectively, involvement workers need to have adequate time for the job, administrative support, access to funding for involvement activities, and ongoing supervision and management support in what can be a difficult and isolated role.

An involvement worker post typically includes having the time, skill and authority to:

- persuade sceptics;
- constantly challenge others to ensure that the level of user empowerment achieved (see Section Two) is optimal and not tokenistic or paternalistic;
- engage staff and harness staff commitment;
- link with leading edge practice nationally;
- provide information and training about methods

and techniques of involving people with dementia;

- demonstrate, and help staff to test out, ways of working;
- provide a role model for staff;
- provide advice and encouragement;
- provide a framework to keep staff focused on objectives and timescales;
- provide prompt feedback and encourage reflection on practice;
- co-ordinate activity and promote networking with a view to mutual support, shared learning and reduced duplication of effort;
- provide a link between service staff and senior management to ensure that people at all levels in the organisation are aware of the factors affecting support for, and implementation of, involvement work;
- highlight the resources required;
- keep involvement high on other managers’ agendas;
- contribute to the development of policies and procedures relating to involvement of people with dementia, for example, the consent process;
- facilitate agency-wide and cross-agency awareness and activities in involving people with dementia;
- facilitate the strategic development of the involvement of people with dementia in close collaboration with other service specific, and generic, service user involvement programmes;
- monitor and collate the activities and outcomes of involvement work and report to senior managers on follow-up action in response to requests and suggestions made by people with dementia.

The crucial feature of the involvement worker role is that the postholder is able to engage on a micro level, keeping in regular contact with and supporting those actively involving people with dementia, but also able to ‘manage up’ in influencing senior support for, and responsiveness to the outcomes of, involvement activities. In addition, involvement workers who are engaged in multi-agency initiatives, need to be able to establish and develop their networks with senior managers across health and social care agencies. A summary of the qualities, skills and experience that involvement workers need is provided in Box 3.1.

BOX 3.1: INVOLVEMENT WORKER QUALITIES, SKILLS AND EXPERIENCE

- Expertise and experience in dementia in order to ensure credibility with staff, managers, service users and relatives;
- good communication skills with people with dementia, carers, staff and managers;
- tenacity;
- enthusiasm;
- ability to inspire enthusiasm in others;
- clarity of thought and purpose;
- good organisational abilities;
- a vision for overall involvement within the service and skills in strategic planning;
- the ability to work at all levels of involvement;
- the ability to co-ordinate involvement activity across the organisation(s);
- ability to network effectively with the wider involvement community;
- the ability to set up reporting systems to ensure that the responses of people with dementia can be collated and used effectively to influence wider service planning and development;
- the ability to put in place systems for monitoring and evaluation.

STAFF SUPPORT AND PRACTICE DEVELOPMENT

Dementia involvement workers are in a field in which there is relatively little in the way of established 'best practice' guidance. It is important that managers promote practice development. One way to do this is to encourage workers to meet with other involvement workers in related fields, perhaps in learning disability, mental health or older people's services, to reflect on practice issues and assessing the value of what they are doing. Services can

encourage such processes of mutual review either amongst workers within the organisation or by linking workers with the staff of other agencies.

Managers should also consider how they can demonstrate to staff that involvement work with people with dementia is valued. This is important for all staff, but all the more so for the care staff who are in the lowest paid and lowest status positions. Example 3.2 describes how this issue was raised in one involvement project.

EXAMPLE 3.2: RECOGNISING STAFF EFFORTS

A group of five home care assistants and their 'senior' took part in an involvement project. Towards the end of their project they asked the lead manager whether their contribution would be formally acknowledged by the local Council (their employing organisation). *"I want something to show my family"*, said one home care assistant. They made it clear, however, that they were not asking for financial reward but rather acknowledgement that this work was special as they were incredibly proud of their achievements. The lead manager decided to look into the possibility of them being presented with a certificate in recognition of their valuable work.

MONITORING, REVIEW AND EVALUATION

One task for managers in promoting the involvement of people with dementia is to monitor how the level and type of activity in their organisation changes over time and how it compares with the level and type of activity for other user groups.

In the field of user involvement generally there are many accounts of the processes of involvement with different groups but limited evaluation of the impact or outcome.^{28,33,40} Since the involvement of people with dementia is at an early stage of development, it is not surprising to find little work that has been evaluated. The focus to date has generally been one of piloting approaches and refining activities based on learning from practice. Since we still have a great deal to learn about 'what works well', the need is for much more exploration and piloting of different approaches to involving people with dementia. Managers therefore need to encourage staff to try out new ideas in a context of ongoing learning through reflection and review. They should also consider how learning within their organisation can be shared more widely and contribute more generally to raising expectations and expertise in involvement work with people with dementia.

KEY POINTS FOR MANAGEMENT

- Provide strong leadership in promoting involvement for people with dementia.
- Demonstrate the organisation's value commitment to involving people with dementia;
- Promote an organisational culture that challenges negative assumptions about the lack of ability of people with dementia to be involved in service development.
- Assess how the organisation is currently operating in relation to involving people with dementia.
- Ensure that there are arrangements to involve relatives of people with dementia in their own right.
- Ensure appropriate training and development activities are available for people with dementia who want to develop their confidence and skills in involvement work.
- Harness the expertise that exists amongst staff in dementia care.
- Support staff who are prepared to question long held practices, attitudes and beliefs.
- Provide staff with training and development opportunities to enhance their skills and confidence in this work.
- Ensure that ethical guidance is available to staff.
- Give staff dedicated time and the other resources needed to develop this work.
- Ensure good leadership from specialist, expert dementia involvement worker(s).
- Encourage staff to try new ways of working in a context of ongoing learning through reflection and review.
- Ensure that the views shared by people with dementia during different involvement activities are collated to ensure maximum impact.
- Ensure staff and middle managers undertaking involvement work understand the strategic planning and financial cycles into which user views must feed.
- Ensure that there are clear arrangements for staff and managers to convey service user feedback on inter-agency matters.
- Ensure that issues raised by people with dementia are taken seriously and that the people involved receive feedback about follow-up actions.

SECTION FOUR: PRACTICE MATTERS

INTRODUCTION

When staff with ideas about how to involve people with dementia have an opportunity to put their ideas into action they are likely to want to start immediately. Such enthusiasm and initiative must be welcomed and encouraged, but it needs to be accompanied by careful planning and preparation to ensure that the time and energies of the people with dementia who are involved are valued and used to best effect. Most importantly, planning and preparation should include ensuring that people with dementia are involved as early as possible in shaping the activities and determining the extent to which they will have control.

This chapter concentrates on practice issues encountered by staff, in statutory and voluntary sector organisations, who are engaged in work to involve people with dementia. Section Two discusses the range of activities that staff might use. In this section we focus on practical and ethical issues in setting up and running involvement activities, and staff roles and responsibilities in the process.

MARSHALLING SUPPORT

Since dementia involvement activities are complex and likely to require the co-operation and support of a range of people, they are often planned and overseen by a group of practitioners working together, perhaps with the assistance of a specialist involvement facilitator. Groups coming together to develop the involvement of people with dementia have themselves to become established and their members to go through processes of negotiating roles, relationships and purposes with each other⁴¹.

The membership of any working group needs to be carefully considered to ensure that all relevant interests are represented, including consideration of membership by people with dementia. Arrangements for chairing or facilitating the group also need to be clear otherwise the group will be in danger of being poorly co-ordinated and losing momentum. It is important that the chair or facilitator not only has sufficient time to prepare for each meeting but also administrative support for circulating reminders and

agendas to the participants; taking notes and circulating minutes; organising room bookings and ordering refreshments. Group members must also be made aware of the amount of time that they will need to devote should they agree to join the working group. This is likely to involve time spent undertaking tasks outside of the main working group meetings, possibly in smaller sub-groups.

When there is no formal working group, staff planning a consultation or involvement activity may find it useful to spend time together so that they can get to know one another better, share their expectations and clarify their individual roles and responsibilities. For example, one group of staff working across a range of statutory and voluntary organisations undertook a short person-centred care training course together to encourage team building as well as to help them to increase their knowledge and awareness about good quality dementia care prior to embarking on their planned initiatives.

PLANNING THE ACTIVITY

Ideally local managers will have engaged with staff in discussions about the level and purpose of involvement to provide them with a context in which to develop their work (see Section Three). Here we focus on the detailed planning of involvement activities that needs to be undertaken by the staff who are familiar with the service context and the people with dementia who will participate.

Experience has shown that staff, regardless of seniority, who have limited or no experience of consultation and involvement activity, are often apprehensive about the prospect. It is therefore often advisable to start on a small scale, possibly working with a group of service users with whom staff are familiar, so that everyone involved can build up their confidence.

The most important thing to stress is that there are few 'right' answers about which people with dementia to involve and which activities to undertake with them. It is very much the case that one-activity-doesn't-fit all! A range of activities are likely to be required to suit people's preferences and varying cognitive and communication abilities. Even when

plans are well made, there are often unforeseen circumstances or unpredicted responses to deal with. It therefore helps if staff can approach the planning and implementation of involvement work with an attitude of 'learning by doing', as long as this is underpinned by a sound value framework and ethical stance (see below).

Factors to take into account in deciding about activities are summarised in Box 4.1.

CLARIFYING WHO WILL PARTICIPATE

When planning a consultation or involvement activity it is useful to have clear criteria, about who will participate. The criteria need to take into account the agreed scale and purpose of the activity, the heterogeneity of the population of people with dementia (in terms of age, gender, social and ethnic backgrounds, physical ability, education, type and degree of dementia and so on), and risks that some

groups will be marginalized and excluded.^{42,43} So far the people who have been most active in user involvement initiatives in dementia care have been people experiencing the earlier stages of dementia, and mainly people with younger onset dementia. If the plan is to ensure broad inclusion of people with dementia, then staff will have to be proactive in facilitating the inclusion of 'hard to reach' groups (see Appendix 1) such as people from minority ethnic communities, people in rural communities, people who are unable to leave their homes and people with more advanced dementia. If the plan is for more targeted involvement, for example on the basis of service use or degree of dementia, then clear criteria are important for explaining to people with dementia and others why it is that only some people can be involved. It is likely that sometimes constraints on who can be involved will result from resource limitations. It is important that staff are open in explaining any such limitations and that, where

BOX 4.1: QUESTIONS FOR STAFF IN PLANNING INVOLVEMENT ACTIVITIES

- Have you discussed your ideas with managers to check how they fit within the organisation's overall involvement approach and what support you can expect?
- What type of information/feedback do you hope to gain from the people with dementia?
- Do you intend to involve people from a geographical area, from specific service settings, or from social or support groups that are already established?
- Do you intend to involve people in relation to particular aspects of the experience of dementia, for example diagnosis and early dementia?
- How many people with dementia are you likely to be able to involve, how keen are they and how much time are they willing and able to give?
- What activities would the people with dementia prefer?
- What activities best suit the strengths, levels of comprehension, verbal communication abilities, physical abilities and social circumstances of the people who will be involved?
- Has a similar involvement or consultative activity been undertaken elsewhere? If so, what lessons can you learn from that experience?
- What level of support, if any, will the people with dementia need to enable them to participate to their full potential?
- What resources will be available (funding, stationary, administrative support, transport, venues for events and so on)?
- How many staff and volunteers are available and willing to offer assistance?
- Do staff and volunteers have the required confidence, experience and expertise or do they have training needs to be met prior to embarking upon the work?

appropriate, they provide their managers with feedback about the resources needed to address gaps that exist in the involvement opportunities available.

INVITING PEOPLE WITH DEMENTIA TO PARTICIPATE

Staff who are initiating involvement activities should ensure that people with dementia are involved from the earliest possible stage. They need to do this with an awareness that most people with dementia will have experienced a service culture that has been disempowering and disregarding of their subjective experiences and they may as a result lack confidence in their own abilities to contribute or be sceptical about staff's intentions.

For staff working or meeting with people with dementia on a day-to-day basis, finding people to involve should not be too difficult. How each potential participant should be approached and invited to take part will depend upon a range of factors, including: how well they are known to the staff; their cognitive and communication abilities; and their culture and social circumstances. A range of approaches may be useful in different circumstances, for example: posting an invitation letter to services users; handing a letter to the service user and their supporter or carer during a service appointment along with a verbal explanation and opportunity to ask questions; having service providers personally invite people for whom they provide care; producing posters, perhaps designed by people with dementia, inviting other people to join them.

Staff embarking on involvement activities who do not have direct contact with the people with dementia whom they want to involve, will have to engage the help of others in marketing the activity and 'recruiting' participants. People who might be asked to help could, depending on the nature of the activity, include for example:

- GPs and consultants
- staff and managers in community mental health teams, home care, social services care management, day services, care homes;
- staff and volunteers in Alzheimer's Society branches and other voluntary organisations;
- community workers, community groups, and religious and ethnic group leaders.

If the aim is for broad inclusion of people with dementia, a well thought through strategy for accessing harder to reach groups of people will be required (see Appendix 1). In addition to the above, the use of local media, such as features within local newspapers and radio programmes may prove useful as might contact with local community groups and eye-catching posters in local shops and community centres.

WORKING WITH FAMILY MEMBERS

Family members can have an important role in facilitating the involvement of people with dementia. In particular, relatives can provide information that can help staff understand and communicate more effectively with the person with dementia (see Example 4.1).

In some situations, relatives can adversely affect the involvement of people with dementia. Including relatives at involvement events runs the risk that they will speak on behalf of the person with dementia. For example, during a round of introductions within a meeting attended by several people with dementia and their relatives, one carer introduced her husband, to his obvious irritation, rather than giving him time to introduce himself. In such situations, staff need to find ways of empowering the person with dementia while ensuring that family members do not feel undermined.

In most involvement activities, family members actively support and encourage people with

EXAMPLE 4.1: A RELATIVE FACILITATING THE INVOLVEMENT OF A PERSON WITH DEMENTIA

One person with dementia's involvement in a consultation event was made more difficult by her deafness. With her daughter alongside giving prompts, she was helped to participate effectively. For example, she was initially unable to recall her home help or the assistance she had received. But when her daughter reminded her that it was "the lady who used to work in the shop" she was able to recall what the home help did for her.

dementia to become involved. However, the IPWDP experience included examples of relatives voicing scepticism about the value of involvement, expressing fears that involvement might have detrimental effects upon the well being and functioning of the person with dementia, and even strongly opposing people with dementia being asked to join a committee.

It is important to remember that family members have their own perspectives that equally should be listened to. Staff may need to discuss with their managers how relatives might be involved in service planning and development without inhibiting the contributions of people with dementia.

ENSURING ETHICAL PRACTICE

It is a fundamental principle of involvement work that it must be value based and ethically sound (see Section Two). Staff embarking on any involvement initiatives with people with dementia should seek guidance from their organisation about governance and ethical requirements. Some involvement activities may be deemed to be research and to require approval from the Local Research Ethics Committee. This process may take several weeks and therefore needs to be taken into account in the early planning stages to ensure realistic timescales are set.

No matter what degree of dementia someone is experiencing, their consent should be obtained before their views are sought, formally recorded and used to influence service planning and development. For some people with dementia giving consent may be a relatively straightforward process as they will be able to provide their verbal and/or written consent,

particularly in the early stages of the disease. For those people who have impaired ability to comprehend, process, and weigh up information, giving consent is a more complex issue. In many cases a person's level of functioning will fluctuate. In such circumstances, an assessment of the person's ability to provide their informed consent must be made at the time they are being asked to decide whether or not they wish to participate.

Consent forms are sometimes used with people with dementia but there are often problems in that insisting on written consent can lead to large numbers of people with dementia being excluded from the consultation or involvement activity as they are unable to give this level of informed consent. Proxy consent by the relatives of people with dementia is an approach that is sometimes used, but this does not sit altogether comfortably with the ethos of involvement work.

It is quite usual for involvement activities to operate on the basis of 'process consent'.¹³ Process consent involves ongoing explanation about the nature and purpose of the consultation or involvement activity and ongoing negotiation to determine if the person remains willing to offer their expertise and opinions. The level of explanation provided about the involvement activity, and the way in which consent is determined, varies from one person to another, depending upon their levels of awareness, comprehension, verbal and non verbal abilities and so on. If a person with dementia is unable to clearly express an informed decision regarding their willingness to participate, staff may rely on their interpretation of the person's non-verbal reactions. For example, if the person seems happy and relaxed

BOX 4.2: WORKING WITH FAMILY SUPPORTERS IN INVOLVING PEOPLE WITH DEMENTIA

- Provide relatives with a clear description of why people with dementia should be involved and the process that is planned.
- Include relatives in events only where there is no conflict of interest between their perspective and the wishes of the person with dementia.
- Enable relatives where appropriate to advocate for people with dementia.
- Ensure that, in joint consultation events with relatives and people with dementia, the relatives' views do not overwhelm those of people with dementia.
- Provide relatives with opportunities to be involved in their own right and separately from involvement activities with people with dementia.

EXAMPLE 4.2: ETHICAL ISSUES

In one consultation and involvement activity, workers found that people with dementia frequently expressed feelings, preferences and ideas that were relevant to their own individual current and future care. Staff thought that it was unethical to ignore this valuable information. With the person's permission, the involvement workers contacted the services responsible for co-ordinating the individual's care package to ensure that their views were taken into account.

BOX 4.3: SUGGESTIONS ABOUT DEALING WITH CONSENT AND OTHER ETHICAL ISSUES

- Treat consent as an ongoing process not a one-off decision.
- Explain the nature of the involvement activity to the person with dementia, particularly what information you will be recording and how this information will be used.
- Record how consent is obtained at the beginning and throughout the involvement process.
- Build in processes to check that any views or ideas from the involvement process are agreed and prioritised by the people with dementia concerned and are not unduly influenced by other participants in the involvement process.
- Continually reflect on what you are doing, why and in whose interests.
- Ensure that confidentiality is maintained and that you have consent before sharing information with others in the family or the service system.
- Ensure that you are familiar with agency policies and procedures and know how to respond to any revelations of abuse or poor practice.
- Ensure that you receive regular supervision in which potential and actual ethical issues are identified and discussed with clear recording of agreed action and the reasoning underpinning those actions.
- Ensure that you have received appropriate training/education on issues of capacity, consent, human rights and other ethical issues.

and does not appear to be in any way disturbed or distressed by the explanation or the activity, staff may take this as an indication that, at that specific period in time, the person is willing to participate. Throughout the consultation or involvement activity, the person's non-verbal reactions would be closely observed to determine if they still appear willing to continue their involvement. If they begin at any time to show signs of anxiety, agitation or upset or they simply get up and walk away from the member of staff or the group activity in which they are taking part, this would be deemed to indicate a withdrawal of consent.

There are a range of other ethical matters that

practitioners may encounter and they should ensure that they are clear about the requirements of ethical practice and procedures in relation to: maintaining confidentiality, protecting individuals' identities, ensuring that participation has no detrimental consequences for the individual's wellbeing or the services that they receive, and dealing with any abuse or poor practice that comes to light. Example 4.2 provides an illustration of some ethical issues encountered in practice and Box 4.3 summarises some suggestions to help in dealing with ethical issues in practice.

Additional sources of advice on ethical matters are contained in Appendix 1

COMMUNICATING WITH PEOPLE WITH DEMENTIA

'We know what we want, but we can't say it. In my view we are not cognitively impaired but communication impaired. Speaking, reading, writing, numbers have all become scrambled. The wires in our head that once did this all somehow automatically, have now burnt out. They are misfiring, becoming crossed over, or absent. As a result, our struggle to communicate increases each day.'

(Bryden 2005, p117-8)¹⁶

'Dementia is a disability, in that it makes communication harder but not impossible. It is only the behaviour of others, in not listening hard enough or well enough, that changes this disability into a handicap'.

(Cheston et al 2000, p478)³⁹

Whatever involvement activities are used, individual or group based, good communication with people with dementia is essential. It can be relatively straightforward to involve people with dementia who have a clear understanding of the matter in hand and the ability to convey their views, albeit at their own pace and perhaps with some assistance with communication. However, communication can be difficult in involvement work with people whose verbal and cognitive skills have been affected by the progression of the disease. Being unable to express what they feel or wish to share can create frustration for the person with dementia and for the listener. Example 4.3 illustrates how people with dementia can experience trying to communicate.

The following communication issues need to be considered in planning and undertaking involvement and consultation activities.

Skills

The skills and techniques of good communication in involving people with dementia are essentially the same as those involved in providing good person-centred care.

The advice of one person with dementia about what is required is summarised in Example 4.4. For further advice on communication approaches and skills see Appendix 1.

Shared understanding and language

Before embarking on involvement activities, it is essential that workers find out how the people with dementia involved understand and speak about their condition and, more specifically, what terms are familiar and acceptable to them. Workers need in particular to know: whether or not the person acknowledges that they have a memory difficulty or cognitive impairment, how the person refers to their dementia and how they refer to services. Some people may not know their diagnosis or have forgotten it and people may have limited recall or understanding of the nature of the service support they receive. For example, one person involved in an IPWDP case study, described home support workers as the *"four girls"* and an evening sitter as the *"Tuesday lady"*.

Trial and error

Experience of involvement activities shows that staff investment of time and energy in planning their communication strategies is well spent. However, experience also suggests that intuition and 'trial and error' are also important contributors to achieving good communication.

EXAMPLE 4.3 COMMUNICATION FOR PEOPLE WITH DEMENTIA

"On occasion I feel that I am being shut down, pushed down to get me out of the way...If I want to do something, someone else does it."

"when I'm belittled, that's when it hurts... When people speak down to me. Unless I'm just being hypersensitive."

"I just feel a bit of a fool at times. Especially when I can't get my words out, because they won't come. And in any event they are all jibberish."

EXAMPLE 4.4: COMMUNICATION SKILLS: WHAT PEOPLE WITH DEMENTIA NEED

'I operate in a different way to you, and need a different type of interaction, which is slower and more meaningful. People want to be busy, to talk fast, to ask for responses, but I can't cope with that. I need a restful, calm environment, with no visual or aural distractions, to listen to what you say and to be able to speak to you...

Just because we can't express ourselves very well does not mean we have nothing to say. As our thoughts and words are tangled and confused, you will need good listening skills, being attentive to non-verbal cues. Take what we say in context, as the words and their order will be wrong. Try to find the meaning behind the words as we will make mistakes in tenses, words and grammar. Be sure we would like you to help fill in the gaps in our struggle to find words and sentences before you do so. Don't correct us, just try to understand the meaning of what we intend to say.

Don't interrupt our thread of thought, but let us interrupt you when an idea comes into our head, because if we wait, it will disappear. Try the technique of reflective listening, where you repeat back what we have said to you, not exactly, but repeating the meaning of what we have tried to say. This will help to ensure you have understood our true meaning, and help us to feel really listened to.

Give us time to speak, wait for us to find the word we want to use, and don't let us feel embarrassed if we lose the thread of what we say...

Try to avoid direct questions, which can alarm us or make us feel very uncomfortable. Questions also make us feel pressured for the immediacy we have lost. If we have forgotten something special that happened recently, don't assume we didn't enjoy it. Just give us a gentle prompt – we may just be momentarily blank...

It is best to look at us, to make sure there is eye contact and that we are attending from the beginning of what you say. Speak clearly and not too fast. Slow down when you speak, so we can follow you, for we will have gaps in reception and understanding – and the faster that you talk, the more we will miss. Don't shout at us though – the problem is often not our hearing, but our understanding. Shouting simply distresses us – for me it feels as if you are hitting my head, causing even more confusion inside there.

Most importantly, don't push us into something, because we can't think or speak fast enough to let you know whether we agree. Try to give us time to respond – to let you know whether we really want to do it. Being forced into things makes us upset or aggressive, even fearful.

Look behind our behaviour to its meaning, as we communicate with you in this way. You can enter into our reality, accept more emotion and feeling, and connect with us at this level as our cognition fails and inhibitions decrease.

Touching us, to connect with us, may be helpful. Many of us may not like to be touched by people we do not know...

Observing us will be the key to knowing what we are saying to you. Most of our communication is non-verbal. Our facial expressions, our hand gestures, and the context in which we are trying to communicate with you are all important.'

(Bryden 2005, pp139–141)¹⁶

EXAMPLE 4.5: BEING PREPARED TO INNOVATE

A nurse had prepared a series of written questions in advance of a consultative meeting. The questions were intended to capture people's feedback on the information provided to them by a local memory clinic. This activity did not go well as the four people with dementia appeared to have very little recollection of the clinic or the information it had made available to them. Improvisation was needed, quickly.

Another nurse scribbled the word 'information' down on the blank flipchart paper that was laid out on the table. One person with dementia took hold of the pen and filled the paper with words and statements triggered by this one word. Another spoke of the things that tended to attract their interest to a leaflet. The conversation stimulated people's memory of the clinic, leading to one person suggesting that reminder cards could be sent out to service users and their family to prevent people missing their appointments. After the initial flurry of discussion, people began to lose interest in this activity after ten to fifteen minutes. The conversation naturally flowed onto holidays, family and other interests for the remaining half an hour.

Staff seeking to consult and involve people with dementia should be sufficiently confident to risk 'trial and error' when communicating with people with dementia. Experience shows that being innovative, and trying different approaches or a change of worker, can be effective with people who are reticent about expressing their views or feelings. This is illustrated in Example 4.5.

Quality of relationships

The quality of communication in involvement work is closely linked with the quality of the relationships, whether short or long-term, that involvement workers develop with people with dementia. It is important that workers spend time developing good rapport with people with dementia before embarking on a consultation or involvement exercise. In particular, they need gradually to build up a picture of the person's preferred interaction styles and ways in which they might best be enabled to participate.

As the individual or group becomes more relaxed and settled in the company of the workers with whom they are sharing their experiences and opinions, their views and responses may change. Staff must be sensitive to differences between a person's public presentation of views and more privately held opinions that might be revealed within a strong and supportive relationship.

Pace of communication

One of the most important requirements of good communication with people with dementia is pace. The thought and response times of people with dementia will be slowed to varying degrees. Within a group, participants may include people with a range

of comprehension and communication abilities. Involvement workers must be aware of the need to pace interaction, particularly the number of topics or questions being discussed and the amount of information conveyed.

Non-verbal communication

Staff embarking on involvement activities should be aware that some people with dementia who are assumed to have lost their verbal skills, may still have language that can be retrieved if they receive the appropriate response and empathy from staff. However, for some people with more advanced dementia, non-verbal communication may be their main means of expressing their preferences.

Involving people with more advanced dementia raises particular communication challenges for workers to develop appropriate skills and techniques. It is also important that workers make allowance for the extra time, commitment and patience needed in working with people whose verbal communication is seriously impaired.

Visual prompts

Even with people with dementia who retain good verbal skills, pictures and visual prompts can be very helpful in obtaining people's views and preferences. For example, it may be more meaningful for someone who is being consulted about bedroom décor in a residential home to be asked questions in their room where there are lots of visual prompts. When topics are more general, it can be useful to use pictures (for example of different people, places, or social or service activities) to elicit views about these aspects of life.

Fluctuating abilities

A person's mood, level of concentration and willingness to enter into conversation may fluctuate in different settings, but also at different times of the day and in response to other factors. Involvement workers need to be able to recognise these differences and know when to involve individuals and when to leave it to another day or time.

Staff must also be aware that their own mood, level of tiredness and ability to concentrate will affect their communication with the people they support.

Changes over time

As the individual's dementia develops, there will be changes in their communication skills and ability to participate in different activities. It is important that involvement workers anticipate this change and have plans for how this will be handled (see below).

Sensory impairments

Some people with dementia have sensory impairment needs that must be taken into account. A visually impaired client may need to be assisted with 'signals' that help them to identify who they are talking to. For example, one person with dementia recognised a support worker by touching a piece of jewellery and frequently talked to the other workers about the *"lady who calls with the ring on her necklace"*. If the person with dementia has a hearing impairment, visual clues and prompts, for example, pictures and photographs of staff, living environments or food, may be particularly helpful when discussing a service.

Culture and language

Effective communication requires cultural understanding and sensitivity in practice. In addition, there may be language barriers with older members of minority ethnic communities, who have acquired only limited use of English or who have lost their memory of the language as their dementia develops (see Appendix 1). It is therefore important that involvement workers have access to people who have the necessary language skills and cultural understanding to act as interpreters. While family members can often assist with this, this is not always an acceptable option for them or the person with dementia. Alternative arrangements should therefore be available.

INVOLVING INDIVIDUALS AS CONSULTANTS OR ADVISORS

Increasingly staff should be thinking about opportunities to involve people with dementia directly in planning and monitoring the delivery of services. Individuals with dementia might serve as members of planning groups, management committees or staff selection panels, or might contribute to staff training or appraisals. People with dementia who wish to act in this capacity should be enabled to do so, with support as necessary to contribute effectively. Box 4.4 provides suggestions about how people with dementia can be supported in this type of work.

RUNNING GROUP EVENTS AND ACTIVITIES

Often involvement activities bring together a number of people with dementia to express their views and feelings. Sometimes this happens in a one-off event, sometimes in a series of events, and sometimes with an established group of people who meet regularly for social activities or self-help purposes. In this section our comments about supporting 'groups' are generally as relevant to single event groups as to ongoing, established groups.

Whose agenda?

Whether involving people in occasional events or in an established group, it is important that they have the opportunity to shape the agenda and that staff do not impose this on them. Even in occasional events it is important to allow time to agree the purpose of the activity, how it will be organised, the ground rules of participation, and how discussions and actions will be recorded.

When an activity is being undertaken in a series of events, or by an ongoing group, it is essential that staff facilitating such activities avoid making assumptions about what is best for the group. So, for example, at the first event people with dementia should have the opportunity to discuss future venues, the most suitable times for meeting and so on.

If both relatives and people with dementia participate in the activity, it is important to discuss with the group what pattern of joint and separate activities they want built into the programme. This discussion needs to be handled sensitively as both people with dementia and relatives may feel unprepared, suspicious or threatened by the prospect of being separated. If relatives and people with dementia are staying together throughout the activity, staff need to

BOX 4.4: SUGGESTIONS FOR SUPPORTING PEOPLE AS CONSULTANTS OR ADVISORS

- Arrange meetings at times that best suit the person with dementia.
- Meet in suitable venues with good ventilation, comfortable seating and good acoustics.
- Ensure good signage and access to meeting rooms.
- Keep the pace and length of meetings to suit the person with dementia.
- Arrange for minutes of meetings to be sent out well in advance and offer for someone to go through the minutes with the person with dementia.
- Arrange for audio recording and transcription of meetings to aid detailed recall for people with dementia.
- Offer to provide a supporter to meet the person with dementia prior to the event to brief them and help them prepare their contribution.
- Allow people with dementia to discuss issues as they think of them rather than stick rigidly to the agenda.
- Avoid direct questioning of people with dementia.
- Avoid jargon in writing and when communicating verbally.
- Provide stimulus material to aid discussion of abstract ideas.
- Arrange for supporters (relatives, staff or advocates) to help people with dementia during the meeting if they require it.
- Meet out of pocket expenses and give appropriate remuneration promptly.
- Ensure that participants, and their supporters, are told that their expert contribution is valued and that they are thanked for it.

discuss with them how they can ensure that everyone has the opportunity to express their views and how any differences will be elicited and respected.

Group members should direct the way in which they want the group to evolve. Staff should build in regular opportunities for group members to express their preferences, needs and ideas about the focus of the group, its membership and its duration.

Once a group of people with dementia has become established and known for their involvement in planning and service development, they are likely to find that they are invited to become involved in a wider range of activities being undertaken by services in other areas, by researchers, and by the media. While such opportunities are welcome confirmation that group members are valued as experts, such involvement requests can place heavy

demands upon people's time and energy. Group members should be encouraged to choose which, if any, invitations they want to take up. They may need support in negotiating their contribution with other people and in turning down unwanted invitations.

Ensuring a good experience

In order to plan group involvement activity effectively, and to ensure that people are enabled to participate fully, it is helpful for staff to map the person with dementia's journey through the proposed experience. For example, they can map out the different experiences that people will have at different stages of their journey through an activity: preparing to go, leaving their home, travelling, arriving at the venue and finding the room, initial meeting and greeting, finding cloakrooms and refreshments, participating in activities and discussion, returning home. This process can assist in ensuring that the range of

BOX 4.5: SELECTING A VENUE

- Is the venue familiar and acceptable to people with dementia and their relatives? If it is associated with a particular service or organisation, is this acceptable to potential members or would they prefer to meet in a neutral venue?
- Is the venue accessible? For example, is it on a local bus route that is well served, particularly around the start and finish times of the meetings? Is it likely to be central for most people or will some people need to travel a long distance? Is the venue easy to find/well signposted? Is there disabled access?
- Are the toilets near to the meeting room? Are there clear directions to the toilets and back to the meeting room?
- Is there ample car parking?
- Is it safe and non-threatening? For example, is it in an area with a high crime rate? Is it regularly vandalised? Is it in a well-lit area? Can people wait in a safe area for their transport to arrive?
- Does it feel comfortable and welcoming?
- Are the furnishings comfortable and suited to the planned activities?
- Are there likely to be interruptions and distractions?
- Can the space be used flexibly? For instance, if more people arrive than was originally anticipated is there space to accommodate them without too much upheaval? Can the space be used for activity based group work? Is there a quiet area to talk with someone on a one-to-one basis if they become upset or want to talk privately?
- Are there adequate kitchen amenities with tea and coffee making facilities?
- Will a staff member be a designated key holder with responsibility for opening up and locking up at the end? How will this be managed if staff are needed to transport the participants to and from the meeting?

practical issues that arise in running any activity of this kind are identified and addressed as they will affect the people with dementia involved. This will include: room space, toilet facilities, appropriate furniture, catering, transport, equipment, administrative support, reimbursing expenses and social and emotional support.

Within any group there will be variation in the needs of individuals. It is important that staff assess each participant's support needs prior to their attendance at the group and build in suitable support. For example some people will have particular health, mobility or dietary needs or may want to be accompanied, through all or part of the experience, by someone with whom they are familiar.

Finding a venue

It is important to find the right venue to hold group meetings/activities. This may involve spending time surveying the local area and visiting a range of

places until somewhere is found that is best suited to the purpose of the meetings and the needs of the people who will be attending. For ongoing activities, it is important to consider future availability of venues as change at a later stage may be disruptive for participants.

Box 4.5 summarises important considerations when selecting a venue.

Shaping the programme for each event

It is important that staff are responsive to what people want in an event and avoid pushing topics of discussion on them. Participants will have many things in common apart from their current or potential use of services, and are likely to enjoy talking to one another about their families, their hobbies and interests, recent holidays or past employment. Providing the opportunity for social interaction, such as an informal lunch, within consultation and involvement activities is an ideal

way of allowing people opportunity to enjoy socialising and to form friendships at the same time as making their views heard.

Sensitive negotiation is crucial to ensure that people with dementia shape the programme and determine the topics that they want to talk about. Experience of 'consultation events' suggests that memory problems and views on local services are rarely a 'hot topic' for conversation. Some people are reluctant to talk about their memory difficulties or service use directly. They may feel that they are being 'examined', they may fear losing their services, or they may fear that if they make critical comments they will create trouble for service providers. Indirect approaches can therefore be helpful, particularly at the beginning, to find out how people are most comfortable in expressing their views. For example, stimulating discussion about whether the participants think other people would enjoy a day centre rather than asking what they think of their service.^{13,6}

Many involvement events can be enhanced by giving participants the opportunity to listen to, and speak directly to, service providers, managers, and specialists of their choice, such as consultant psychiatrists, or benefits officials. It is important that 'visitors' are invited at the groups' initiative and requests to attend meetings from any outside professional are put to the group for their agreement before staff agree that anyone should attend.

Guest speakers should be well briefed to:

- speak for only short periods (some people's concentration can lapse after five minutes);
- recap frequently;
- use bullet point presentations to maintain a sharp focus;
- slow down their pace of delivery;
- provide a clear and precise delivery that avoids going off on tangents and interspersing with anecdotes whilst trying to make a point.

Staff facilitation

Facilitators need to be clear about their roles and responsibilities. Whenever possible, and when desired by group participants, the staff role should be to support people with dementia in running the activities or event for themselves. In other circumstances, particularly with people with more advanced dementia, staff may assume a more proactive role, but this should always be done in ways that empower participants as much as possible.

The main tasks for staff facilitators are to ensure that

the group runs smoothly both practically and socially, and that each individual has the best possible opportunity to participate and be heard consistent with a positive experience for the group as a whole. For example, apart from the practicalities of organising event(s), staff may assist people to become orientated, encourage more reticent people to participate, aid people to the toilet if necessary, and deal with any emergency or upset.

It is generally better to have more than one member of staff to support each group. If a large involvement activity or consultation event is planned, it is very important to ensure that sufficient facilitators and co-workers are available and that there is provision to break into a number of small groups. Many people are too shy or nervous to speak up in a big group, and experience suggests that people with dementia and their supporters are generally more comfortable and confident in smaller groups.

While one staff member may take the overall lead, the practical planning and administration of the group and support for the participants is generally shared. Facilitators should have the time and opportunity to get to know one another, share expectations and clarify roles and relationships before the group work begins. Facilitators also need time to reflect on the themes and issues arising from the group. It is important that this is possible shortly after each event.

Some practical suggestions for good facilitation are summarised in Box 4.6.

Managing practicalities

Timing

Plan timing to avoid early starts and late finishes. Although individuals vary, many people with dementia are not at their best early in the morning and some people have lowered energy levels in the late afternoon. Experience suggests that it is best to arrange meetings that start around midday and include lunch.

Reminders

Holding a meeting in the middle of the day allows time for staff to contact participants on the day of the group to remind them of the arrangements and to confirm their attendance.

Transport

Failure to take account of how people with dementia will get to the involvement events can lead to some people being excluded. It is important that

BOX 4.6: SUGGESTIONS FOR GOOD FACILITATION

- Make time to complete preparatory work outside the group events. This includes visiting potential participants to be sure that they understand what will be involved.
- Create a relaxed, informal atmosphere where people can feel safe and able to express themselves without fear of judgement or recrimination.
- Allow people to choose whether or not to participate. Attending a meeting and having a sense of being part of something can be more important to some people than taking an active part.
- Be sensitive to people's differing levels of awareness and understanding.
- Encourage people to participate in whatever way they feel is comfortable.
- Work at the pace of the participants with dementia, not of the staff.
- Make use of smaller discussion groups rather than having everything covered in larger group meetings.
- Ensure that staff do not take the discussion into areas that are not a priority for the participants.
- Check out meanings and interpretations with the group regularly and sensitively.
- Ensure sufficient staff supporters to allow for note taking or assisting the chairperson during the meetings without detracting from supporting participants.
- Use a range of prompts and aids to keep people engaged, such as singing or craft activities, as appropriate. Allow people to disengage and re-engage with the group as they wish.
- If evaluation or comment forms are used, be prepared to support participants who may need help in completing them.
- Ensure that participants, and their supporters, are told that their expert contribution is valued and that they are thanked for it.

If the group is being run by people with dementia:

- Ensure that staff do not interrupt, interject or 'take over'.
- Encourage participants to share tasks around the group, with support as necessary, to avoid too much falling onto the shoulders of one or two group members.
- If a person with dementia is chairing the meeting, the facilitator should discuss with them in advance what assistance they might need and how they would like it to be provided.

acceptable and reliable transport arrangements are in place based upon an assessment of individual needs and any presenting or potential risks. Staff should not assume that everyone will be willing to travel in NHS or social services transport and should consider alternatives including providing information about the availability and timing of public transport, and funding taxis. If a regular driver or transport service is used, it is important that a backup driver, who is known to the person with dementia, is

available. If staff plan to collect people from their homes and return them following the events, they need to ensure that they have made allowance for the time involved and any implications for their pre-event preparation and post-event reflection.

When a group plans outings or events away from their normal venue, transport needs to be considered carefully, particularly if this involves a departure from familiar arrangements.

Resources

Staff need to ensure either that their organisation(s) will provide the necessary resources to support the activity, or that they can acquire funding for resources from other sources (for example, from local charities). Items that may need to be budgeted for include: room hire, catering, stationary, photocopying, postage, secretarial support, guest speakers' fees and expenses, transport, participants' expenses and costs of outings. Staff should also consider how they will obtain the resources to meet any training and development needs that group members may have, for example, on giving presentations, campaigning, using the internet, word processing, or running a group.

In addition, staff should consider providing financial reward for participants' time, effort and expertise, not only reimbursement of their expenses. This is particularly important when involvement activities are serving the interests of service organisations. The issue of payment for participants needs to be addressed sensitively to take account of people's expectations and whether or not their social security benefits would be adversely affected by accepting a payment in cash or kind. For further advice see Appendix 1.

Recording views, suggestions and action points

There is limited value to an event or activity aimed at consulting and involving people in services if the contributions of participants are not available to others. It is important, however, that individuals and group participants agree to their views being used in service planning and staff should continually confirm that participants are happy that their views are used in this way (see also pp.33–34).

It is advisable to try out a range of recording methods to capture the participants' views and experiences until the most effective, efficient and acceptable style is achieved. Although not all participants will be willing to have their discussions recorded on audiotape, and transcription is time consuming and expensive, this method is the most accurate and can be useful for one off events.

If staff take on the responsibility of note taking it is important that the comments recorded are those provided by people with dementia rather than the opinions of staff. Notes should be written up immediately after the event. They should be written in a style that is accessible to people with dementia and circulated to all participants for their comments and correction.

Example 4.6 shows how staff in two involvement activities approached the issue of recording views and ensuring that group participants were aware of follow-up actions.

EXAMPLE 4.6: KEEPING A RECORD

Recording 1

A day unit holds occasional focus group meetings to give service users an opportunity to influence service operation and development. Staff make a point of reflecting back their interpretation of what has been said to the participants of the focus groups at the end of each meeting. This ensures that the written record of each meeting is a true and accurate description of the views expressed. After each group meeting, an action plan is agreed and typed up by the day unit staff. The action plan details how the staff aim to address each issue or suggestion that has been raised by the group. If any actions cannot be implemented, then reasons are given. The action plans are displayed on the notice board within the day unit. Initially service users paid little attention to this notice board, so staff arranged to display alongside the board some beautiful, eye catching silk paintings produced by other service users.

Recording 2

At one involvement meeting with several people with dementia and their carers, direct quotations of people's comments were recorded. Staff later reproduced key comments in the form of large, laminated prints of colourful speech bubbles. The speech bubbles were laid out on a table during the next meeting to demonstrate to the group how their comments had been interpreted. People immediately picked them up, read them and began discussing them. Participants were impressed by the impact of their comments when displayed in such a visual format.

EXAMPLE 4.7: THE IMPORTANCE OF FOLLOW-UP ACTION

Several months after one service user and carer consultative event had taken place, the group facilitator's promise of a report detailing the feedback gathered had still not been produced. The facilitator had not taken into account the amount of time needed to pull together everyone's feedback. In addition, other work commitments and staff sickness were barriers to the report writing. Offers of assistance from other people had been declined because the facilitator had wanted to produce the report in a particular way and they felt that involving other people might jeopardise this. The lengthy delay in compiling and circulating the report to everyone who had attended and contributed their expertise threatened to discredit, what had been, an enjoyable and successful event.

Follow up action

It is important that staff plan time to complete follow up action outside the group meetings. Staff must also allow time, if necessary, to support people with dementia with the tasks that they need to undertake outside of the meetings. For example: designing leaflets, posters or websites, or meeting with funders.

Example 4.7 provides an account of how the impact of involvement activities can be lost if follow-up action is not well planned.

Time scales and endings

When involvement or consultation activities are planned as one off, or time-limited events, this should be made clear to participants at the start. If a consultation group is to be open-ended, staff should build in regular reviews to evaluate its progress and continued suitability to individual and group needs. Staff and participants should also consider whether, and how, a group might be expanded and new participants included. From a practical perspective this will include managing support needs, transport, size of venue and, changing group dynamics.

Open ended consultation or involvement activity demands that staff prepare for individuals to participate in different ways as the dementia progresses and their abilities change. For some people there may come a time when they do not want, or are not able, to continue attending a group. It is important to consider with members how such future times will be handled, as it can be difficult and upsetting for the individual involved, and for other group members, if they are not foreseen and well planned.

PRACTICE REVIEW AND DEVELOPMENT

Workers often say that they are too busy to spend time on reviewing their work or that they find it difficult to quantify the nature of what they achieve. One way to encourage practice review is for services to adopt the principles of reflective practice.^{44,45,46} Reflective practice can be undertaken individually by each worker, for example, by developing an individual reflective diary (see Box 4.7).

Involvement work with people with dementia is demanding. Facilitators have to cope with all the practical and organisational issues and tensions involved. In the face of pressing organisational agendas, they may struggle to maintain a clear focus on the concerns of the people they are seeking to involve. They also, in working directly with people with dementia, experience many emotional demands, as well as rewards. It is important therefore that facilitators obtain regular support and supervision.

KEY POINTS FOR PRACTICE

Preparing

- Begin work at the earliest possible opportunity to enable time for adequate preparation.
- Ensure that you feel adequately supported and able to facilitate the involvement of people with dementia.
- Ensure that adequate funds are available to support the activity and that people can be financially recompensed if appropriate.
- Check in advance if clients have any vision or hearing difficulties and, if needed, that they have access to their glasses and properly working hearing aids.

BOX 4.7: DEVELOPING A REFLECTIVE DIARY

Reflect on experiences and write up in detail regularly. Consider questions such as:

- What were the practical, social and emotional areas in which the people with dementia needed support to be involved?
- What did staff do that enabled people to be more fully involved?
- Were there areas in which you think more could have been done to enable people to be more fully involved?
- What prevented people with dementia being involved to the full?
- What alternative involvement approaches might be more effective in these circumstances?
- What were the issues on which people with dementia expressed views?
- Has anything changed for the people with dementia as a result of their involvement?
- Has anything changed for other people as a result of the involvement work?
- What contributed to making change happen?
- What, if anything, prevented change happening or made it difficult?
- How do you feel about what has happened and how have you coped with your feelings?
- What were the ethical issues and how were they handled?
- Are there any issues that keep coming up in your work?
- What went well and why?
- What with hindsight would you have done differently?

- Be sensitive to the fact that some people with dementia may be able to participate better at certain times of the day.
- Check in advance if clients are members of a minority ethnic or cultural community and particularly whether an interpreter is needed. Ensure that you take full account of their ethnic and cultural backgrounds and where appropriate enlist the help of others to do this (for example, people from their local community or community organisations, or from advocacy organisations).
- Ensure that each person with dementia has the involvement activity fully explained in advance.
- Consider routine and familiarity in the timing and venues for activities.
- Check that the environment for meetings is suitable (noise levels, privacy, access and so on).
- If people with dementia are participating in formal agency meetings, ensure that meetings

are held at a time, and of a duration, that will be suitable for them.

- Plan for large events to include opportunities for small group discussions.

Introducing people with dementia to consultation and involvement

- Treat people with dementia with respect and ensure that they can maintain their dignity.
- Be sensitive to the individual circumstances of each person with dementia.
- Ensure that the person with dementia feels safe and orientated.
- Explain your role as appropriate for the individual.
- Ensure that the nature and duration of the involvement or consultation activity is explained.
- Establish that the person with dementia is consenting to the process.

Communicating with individuals and groups

- Talk clearly and use simple, straightforward language.
- Build up trust.
- Take time to get to know the people with dementia. It may take several visits or meetings of varying length to establish rapport.
- Adopt a 'softly softly' approach and do not be too intense.
- Try a range of communication tools and techniques, for example, writing things down, visual images.
- Take care that you do not overly 'guide' what the person with dementia is saying.
- Try to find out what is behind what the person with dementia is saying.
- Be alert to non-verbal communication such as facial expressions and body language.
- Use touch sensitively.
- Be aware that you will not always get a response.
- Use your instincts.
- Ensure that options and the consequences of any choices made by an individual or the group are understood.
- Explain any planned action and what might change as a result.
- Check that the participants agree with any views or suggestions recorded.
- If people with dementia are participating in formal meetings, ensure that minutes and other documents are delivered to them well before the meeting to allow them time to consider the content and to prepare to present their views. Provide assistance with this if required.
- Arrange for people with dementia who are participating in formal meetings to be supported, as required, to present their views.

Facilitating the process

- Do not assume that the issues identified for consultation are important issues for the people with dementia. Ask them for their agendas.
- At each meeting spend time prompting and reminding the people with dementia who you are and what you discussed at the previous meeting.
- Take time to talk around the situation, be unhurried.
- Do not try to move people on at a faster pace than they are able to cope with.
- Be aware that there is the possibility that some people with dementia will be subject to poor practice or abuse, and be prepared to deal with this.
- Recognise that the views of the person with dementia may change in the course of a meeting, or from day to day, as well as over longer periods.
- **Concluding**
 - Be alert to cues as to when to leave or to finish a meeting or an event.
 - Consider summarising minutes in audio format.
 - Report back to all who take part to let them know what has happened as a result of their involvement.
 - Take care to present feedback in an accessible way, for example using verbal, audio recorded and written and illustrated formats.
 - Ensure that any out of pocket expenses, payments or other forms of recompense for people with dementia and their supporters are agreed in advance and are arranged and delivered promptly.
 - Plan to enable people to move on to other activities when participation is no longer appropriate for them.
 - Value people's expertise and contribution. Acknowledge the contribution of all taking part (including staff) and say 'thank you'.
 - Consider thanking people by providing a lunch, sending hand written cards or other personalised acknowledgements.
 - Celebrate successes.
 - Learn from doing and share your learning.

CONCLUSION

Involving people with dementia in service planning and development is relatively new. Other areas of health and social care provision have made much progress in listening to the voices of users. Dementia services are, therefore, in a position to build on the experiences of others in a climate of greater openness and accountability. Most significantly, dementia services can now build on the small, but growing, body of innovative work within dementia care. Although much of this work has been small scale and exploratory, it has demonstrated clearly that people with dementia have contributions to make and that it is no longer acceptable to exclude them from the mainstream of service involvement.

This guide has drawn on a review of leading edge

work, and on related literature, to provide ideas and suggestions about good practice in involving people with dementia. It has messages for both managers and practitioners. It has stressed the importance of giving primacy to people with dementia as individuals who have an equal right to be heard. It has also emphasised the importance of wholehearted management support and prioritising of resources.

There is still much research and practice development work to be done to enable us to better hear what people with dementia have to say and to understand how best to empower them. In the meantime, it is clear that people with dementia have found a voice and that we will increasingly hear them saying, "Listen to us."

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APPENDIX 1

FURTHER READING

DEMENTIA

Understanding dementia and person centred care

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APPENDIX 2 USEFUL RESOURCES INVOLVEMENT OF PEOPLE WITH DEMENTIA

Organisation	Contact	Comment
<p>Alzheimer's Society</p> <p>Links to: 'Living with Dementia', a national programme through which people with dementia have become involved in the work of the Alzheimer's Society.</p> <p>links to: Alzheimer's Talking Point A web based discussion forum for people with dementia.</p>	<p>Gordon House 10 Greencoat Place London SW1P 1PH Tel: 020 7306 0606 http://www.alzheimers.org.uk</p> <p>http://www.alzheimers.org.uk/About_our_work/About_the_Society/lwd.htm Alzheimer's Society 11-15 Dix's Field Exeter EX1 1QA Tel: 01392 274327 Email: llwd@alzheimers.org.uk</p>	<p>Main care and research charity for people with dementia, their families and carers in England, Wales and Northern Ireland. The Alzheimer's Society is committed to campaigning for greater involvement of people with dementia in decisions about their lives and in the services supporting them.</p>
<p>Alzheimer Scotland – Action on Dementia</p> <p>Links to: Scottish Dementia Working Group (SDWG)</p>	<p>22 Drumsheugh Gardens Edinburgh EH3 7RN Tel: 0131 243 1453 www.alzscot.org.uk</p> <p>http://www.alzscot.org/pages/sdwg.htm</p>	<p>Provides services and campaigns to help people with dementia, their families and carers.</p> <p>An independent group run by people with dementia and funded by Comic Relief and Alzheimer Scotland. The purpose of the group is to campaign for improved services for people with dementia and to improve attitudes towards people with dementia.</p>

Organisation	Contact	Comment
Dementia Advocacy and Support Network International	www.dasninternational.org	An organisation run for and by people with dementia and their trusted supporters.

OTHER USEFUL ORGANISATIONS – DEMENTIA

Organisation	Contact	Comment
Dementia Services Development Centres		Each centre provides support and information in a specified geographical area in the United Kingdom on all aspects of dementia service provisions to commissioners, service providers and policy makers.
England Dementia North	<p>Details of the English Centres can be found, with links to all sites, on Http://www.dsdcengland.org.uk/</p> <p>Allendale House Northumbria University Coach Lane Newcastle upon Tyne NE7 7XA Tel: 0191 215 6110 Fax: 0191 215 6193 Email: hs.dementianorth@northumbria.ac.uk www.dementianorth.org.uk</p>	<p>Links to the Dementia Services Collaborative www.dementianorth.org.uk/dsc</p> <p>See below for details of the DSC</p>

Organisation	Contact	Comment
North West Dementia Centre	<p>North West Dementia Centre Personal Social Services Research Unit Dover Street Building University of Manchester Oxford Road Manchester M13 9PL Tel: 0161 275 5682 Email: NWDC@man.ac.uk http://www.pssru.man.ac.uk/NWDC.htm</p>	
Trent Dementia Services Development Centre	<p>Department of Psychiatry for the Elderly Leicester General Hospital Gwendolen Road Leicester LE5 4PW Tel: 0116 273 0134 Fax: 0116 273 1115 Email: sdb23@le.ac.uk http://www.trentdsc.org.uk</p>	
Dementia Plus (West Midlands)	<p>Warstones Resource Centre Warstones Drive Wolverhampton WV4 4PG Tel: 01902 575064 Fax: 01902 575051 Email: dementiaplus.wm@wolvespct.nhs.uk http://www.dementiaplus.org.uk</p>	

Organisation	Contact	Comment
Oxford Dementia Centre	Institute of Public Care Roosevelt Drive Oxford OX3 7XR Tel: 01865 761815 Fax: 01865 762015 Email: ipc@brookes.ac.uk http://ipc.brookes.ac.uk/	
London Centre for Dementia Care	Department of Mental Health Sciences University College London Wolfson Building 48 Riding House Street London W1W 7EY Tel: 020 7679 9588/9 Fax: 020 7679 9426 Email: margot.lindsay@ucl.ac.uk http://www.ucl.ac.uk/~rejumil/	
Dementia Services Development Centre South East	Canterbury Christ Church University College Canterbury CT1 1QU Tel: 01227 782702 Email: dscdce@canterbury.ac.uk http://dementiacentre.cant.ac.uk/	

Organisation	Contact	Comment
<p>Dementia Voice</p>	<p>Blackberry Hill Hospital Manors Road Fishponds Bristol BS 16 2EW Tel: 0117 975 4863 Fax: 0177 975 4819 Email: office@dementia-voice.org.uk http://www.dementia-voice.org.uk/</p>	
<p>Scotland Stirling Dementia Services Development Centre</p>	<p>Iris Murdoch Building Applied Social Science Department Faculty of Human Sciences University of Stirling Stirling FK9 4LA Tel: 01786 467740 Email: dement1@stir.ac.uk http://www.dementia.stir.ac.uk/</p>	
<p>Wales DSDC – North Wales</p>	<p>Neuadd Arudwy University of Wales Bangor Holyhead Road Bangor LL57 2PX Tel: 01248 383719. Fax: 01248 382229 Email: dcdc@bangor.ac.uk http://www.bangor.ac.uk/dsc/</p>	

Organisation	Contact	Comment
DSDC – South Wales	<p>Practice Development Unit Whitchurch Hospital Cardiff CF14 7XG Tel: 02920 336073 Fax: 02920 336385 Email: dsdcwales@cardiffandvale.wales.nhs.uk</p>	
<p>Ireland Dementia Services Information and Development Centre</p>	<p>Dementia Services Information and Development Centre Top Floor Hospital 4 St James's Hospital Dublin 8 Ireland Tel: 3531 4162035 Fax: 3531 4103 482 Email: dsidc@stjames.ie www.dementia.ie</p>	
Dementia Services Collaborative	<p>Dementia North Allendale House Northumbria University Coach Lane Newcastle upon Tyne NE7 7XA Tel: 0191 215 6110 Fax: 0191 215 6193 Email: hs.dementianorth@northumbria.ac.uk www.dementianorth.org.uk/dsc/</p>	<p>The Dementia Services Collaborative (DSC) in the North, Yorkshire and North Lincolnshire area is a multi disciplinary and multi agency project. Teams apply the Collaborative Model of Improvement, that aims, through small scale changes, monitoring and review to improve early detection, communication, person-centred care and care coordination for people with dementia and their carers.</p>

Organisation	Contact	Comment
Kingshill Research Centre	Victoria Hospital Okus Road Swindon SN1 4JN Tel: 01793 481 182 www.kingshill-research.org	Provides high quality research information for use in the development of new treatments. Also an information resource for people with dementia and their carers.
Bradford Dementia Group	School of Health Studies University of Bradford 25 Trinity Road Bradford BD5 0BB Tel: 01274 236267 www.brad.ac.uk/acad/health/bdg	Undertakes training and research to promote understanding of dementia and care approaches that improve the quality of life and care for people with dementia and their families.

OTHER USEFUL ORGANISATIONS – GENERAL

Organisation	Contact	Comment
Age Concern	Age Concern England Astral House 1268 London Road London SW 16 4ER Tel: 020 8765 7200 www.ageconcern.org.uk	Has a policy objective to enable older people to participate in society and their local communities. Provides a national information line for older people and their concerns, 0800 00 99 66.

Organisation	Contact	Comment
Care Service Improvement Partnership	www.csip.org.uk	Created to support improvements and development across a range of services in health and local government including those for older people and those experiencing mental distress. Made up of seven different initiatives, including NIMHE, the Health and Social Care Change Agent Team and the Integrated Care Network, CISP works at national, regional and local levels through eight regional development centres.
Centre for Policy on Ageing	25-31 Ironmonger Row London EC1V 3QP Tel: 020 7553 6500 www.cpa.org.uk	Promotes awareness of the needs of older people through the spread of good practice, research and information.
Department for Constitutional Affairs	Seibourne House 54-60 Victoria Street London SW1E 6QW Tel: 020 7210 8500 http://www.dca.gov.uk/	Government Department responsible for ensuring people's rights and responsibilities.
Department of Health	http://www.dh.gov.uk/ Department of health home page	Many departmental publications available in full text format.
Health And Social Care Change Agent Team (CAT)	http://www.changeagentteam.org.uk/ email: change_agent_team@doh.gov.uk Tel: 0207 972 4606	Provide advice and support on a wide range of issues that affect the care of older people.

Organisation	Contact	Comment
Help the Aged	207–221 Pentonville Road London N1 9UZ Tel: 0207 278 1114 www.helptheaged.org.uk	Develops practical solutions in partnership with older people. Offers free advice through Senior Line 0808 800 6565.
Information for Local Government	Info4local Office of the Deputy Prime Minister Zone 7/J3 Eland house Bressenden Place London SW1E 6DU www.info4local.gov.uk	Provides access for local authorities to information from government departments.
Integrated Care Network (ICN)	Room 214 Wellington House 133–155 Waterloo Road London SE 18 6UG http://www.integratedcarenetwork.gov.uk/homepage.php	Provides information and support to organisations to help them to work together to deliver flexible services, and to support communication between frontline organisations and central government.
INVOLVE	Wessex House Upper Market Street Eastleigh SO50 9FD Tel: 0238 651 088 http://www.invo.org.uk/	A national Advisory Group, funded by the Department of Health that promotes the involvement of the public in health and social care research.

Organisation	Contact	Comment
Joseph Rowntree Foundation	The Homestead 40 Water End York YO30 6WP Tel: 01904 629241 http://www.jrf.org.uk	An independent development and social research charity. Useful publications available in full text format.
Mental Health Act Commission Comisiwn Deddf Iechyd Meddwl	Maid Marian House 56 Hounds Gate Nottingham NG1 6BG Tel: 0115 943 7100 http://www.mhac.org	Safeguards the interests of all people detained under the Mental Health Act 1983
Mental Health Foundation	9th Floor Sea Containers House 20 Upper Ground London SE1 9QB Tel: 020 7803 1100 www.mentalhealth.org.uk	Uses research and practical projects to help people survive, recover from and prevent mental health problems. See http://www.mhilli.org/ for information and support for people in later life.
Mind (National Association for Mental Health)	15-19 Broadway Stratford London E15 4BQ Tel: 020 8519 2122 www.mind.org.uk	Provides information and support on mental health issues.

Organisation	Contact	Comment
National Council for Voluntary Organisations	Regent's Wharf 8 All Saints Street London N1 9RL Tel: 020 7713 6161 http://www.ncvo-vol.org.uk/	Umbrella body for the voluntary sector in England that represents views of members to Government, Charity Commission, etc. and provides general advice for the voluntary sector, including approaches to fundraising.
National Institute for Health and Clinical Excellence (NICE)	MidCity Place 71 High Holborn London WC1V6NA Tel: 020 7060 5800 http://www.nice.org.uk	Independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. Includes guidance on anti-dementia drugs.
National Institute for Mental Health in England	http://www.nimhe.org.uk/	Through regional development centres NIMHE provides practical support to mental health service development.
NHS Modernisation Agency	www.modern.nhs.uk	Aims to support organisations in all sectors of the NHS in the task of modernising services and improving experiences.
Sainsbury Centre for Mental Health	The Sainsbury Centre for Mental Health 134-138 Borough High Street London SE1 1LB Tel: 020 7827 8300 http://www.scmh.org.uk/	A charity that carries out research, development and training to influence policy and practice to improve the quality of lives of people with severe mental health problems.

Organisation	Contact	Comment
Scottish Development Centre for Mental Health	17a Graham Street Edinburgh EH6 5QN Tel: 0131 555 5959 sdc@sdcmh.org.uk	A not for profit organisation focused on the development and improvement of mental health services in Scotland.
Social Care Institute for Excellence (SCIE)	Goldings House 2 Hays Lane London SE1 2HB Tel: 020 7189 6840 http://www.scie.org.uk/	An independent organisation that develops and promotes knowledge and good practice in social care. Includes gateway to eLSC (the electronic library for Social Care) and Caredata, which enable on line access to extensive abstracts of relevant social work and social care literature.

DEMENTIA JOURNALS

Organisation	Contact	Comment
Journal of Dementia Care	<p>Hawker Publications Culvert House Culvert Road London SW11 5DH 020 7720 2108 http://dementia.careinfo.org</p>	<p>A multi-disciplinary journal aimed at all people working with people with dementia. Search for articles within the Journal of Dementia Care using topic, date or author since first publication in 1993</p>
Dementia: The international journal of social research and practice	<p>Sage Publications 6 Bonhill Street London EC2A 4PU Tel: 020 73301266 www.sagepub.co.uk</p>	<p>An academic journal that provides good multi-disciplinary cover of practice issues and developments.</p>
Signpost	<p>Cardiff and Vale NHS Trust with Dementia Services Development Centre Wales Tel: 029 2033 6073 http://www.signpostjournal.co.uk/</p>	<p>A specialist quarterly journal aimed at those working with and caring for people with dementia, older people with mental health problems, and their carers.</p>

