

# **Information, advice and advocacy for older people**

## ***Defining and developing services***

**Andrew Dunning**

### **This study explores information, advice and advocacy services for older people.**

Services providing information, advice and advocacy are crucially important in promoting older people's independence. The current context of government initiatives such as Link Age and the growing grassroots advocacy movement of older people make this report both timely and significant.

The report looks at information, advice, and advocacy and the ways in which they may overlap in practice, as well as the differences between them. It explores definitions, core principles, forms, roles and relationships. Information, advice and advocacy are also discussed in terms of skills, services and processes of empowerment. The report focuses on five key themes – accessibility, independence, involvement, strategy and standards. It highlights good practice, and critically examines different ways of thinking about the development of information, advice and advocacy for older people.

The report concludes with suggestions for further work in research, policy and practice. It will be of particular interest to researchers, policy makers, commissioners, and providers of services in all sectors and older people's groups.



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**Andrew Dunning**



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# **1 INTRODUCTION – CONTEXT AND CONTENT**

Information, advice and advocacy are the keys which enable older people to unlock the door to continuing independence and to remain in control of their lives.

(Harding, 1997, p. 3)

Advocacy and information are crucial for effective involvement and their availability is an essential part of getting involved successfully. We include them as components of support for effective involvement.

(Carter and Beresford, 2000, p. 24)

Information, advice and advocacy are services in their own right. They are also fundamental in enabling older people to receive the services they require.

(Quinn *et al.*, 2003, p. 3)

Information, advice and advocacy are crucially important in promoting the independence, involvement and interests of older people. Information, advice and advocacy can help to support an older person in making choices, taking decisions, securing rights, acting in his or her own interests as well as contributing to the life of the community and being fully engaged in society.

## **The information, advice and advocacy needs of older people**

Older people share many of the same information, advice and advocacy needs of people of other ages in the population, and are obviously not a homogeneous group. However, the need for a specific focus on older people in policy and practice arises from a number of life events that affect their information, advice and advocacy requirements (Tinker *et al.*, 1993; Dunning, 1998a).

Such events include the consequences of:

- retirement, which can bring about a reduction of income and social networks
- a decline in physical and mental health, sensory impairment and the need for health and social services
- a change in housing and living arrangements
- ageism.

Moreover, some groups of older people, including those from black and minority ethnic communities and in rural areas, can be further disadvantaged (Department of Health, Social Services Inspectorate, 1998a; Department of Health, Social Services Inspectorate, 1999)

The need for information, advice and advocacy services is not confined to concerns about health and social care or pensions and welfare benefits. It is also concerned with wider aspects of citizenship, including lifelong learning, leisure and employment opportunities. Similarly, such services may be necessary to support older people towards positive participation and preparation for later life – beyond deficit, discrimination and disadvantage (Better Government for Older People, 2000a, 2000b; London Borough of Camden, 2002).

## **Policy, provision and older people**

Since the early 1990s, Government has increasingly recognised the significance of information, advice and advocacy services. Legislation and policy in health and social care in particular have begun to make explicit rights and reference to such forms of support in some circumstances. As the largest users of health and social care services, older people should be the main beneficiaries – and drivers – of these developments.

At a grass-roots level, older people are themselves making demands for information, advice and advocacy. The Health and Older People (HOPE) Reference Group called for these services within the 'new' NHS and the National Service Framework for Older People. The Older People's Advisory Group of the Better Government for Older People national partnership has widened this gaze to take in other areas such as money matters, housing, employment, education and leisure, recommending more broadly that:

Information, advice and advocacy services should be readily available to secure the rights and interests of older people.

(Better Government for Older People, 2000c)

In terms of present provision, generic and specialist information and advice services for older people are available through a variety of sources at national level. These include web sites, telephone helplines and literature provided by government and national voluntary organisations such as Help the Aged, Counsel and Care and Action on Elder Abuse.

Such services are available at local level, too, with statutory health and local authorities as well as voluntary agencies, including Citizens Advice Bureaux and local Age Concern groups, providing

information and advice in a variety of formats and face to face. Though not as established or abundant as information and advice services, local advocacy projects working with older people have also begun to burgeon over the past decade.

## **The need for research**

Information, advice and advocacy for older people are on the agenda of policy makers, providers and older people themselves as never before, and it is important to clarify and critically examine them for a number of reasons.

- To ensure that older people themselves know what to ask for and what to expect from such services and forms of support.
- To establish whether statutory authorities are fulfilling legal requirements and official guidance in some of these areas.
- To identify what is being measured if quality standards are to be applied or if outcomes are to be assessed.
- To specify what is being funded in order to ensure that resources are used for the purposes for which they are intended.
- To be aware of any contested meanings and to challenge definitions and developments where necessary.

A cursory review of research in this field reveals that information and advice for older people is conceptualised and analysed in a variety of ways. Information and advice needs, information- and advice-seeking behaviour, and the production,

provision, take-up and use of information and advice have all been subject to fairly extensive study over the past decade or so (Tinker *et al.*, 1993; Department of Health, Social Services Inspectorate, 1998b; National Audit Office, 2003a).

On the other hand, advocacy with older people is relatively under-researched and little recognised. Advocacy has a hidden history of grass-roots struggles and successes that are largely recorded in 'grey' publications, such as pamphlets, newsletters and documents with limited readerships. However, it is becoming increasingly recognised within the formal body of literature, including academic texts, guidance documents and evaluation reports (Wertheimer, 1993; Dunning, 1995; Atkinson, 1999; Murphy, 2001).

## **Commission and content of this review**

It is against this backdrop that the Joseph Rowntree Foundation commissioned this brief report on information, advice and advocacy for older people, in order to help shape the thinking of its Older People's Programme and to suggest areas for further research and development.

More specifically, the main requirements of the review were to:

- 1 clarify understanding of what is meant by 'information', 'advice' and 'advocacy', and explore ways in which these may overlap in practice, as well as differences between them
- 2 review what is known about older people's perspectives and how they define good services in this area, with a view to developing guidelines to inform local developments

- 3 highlight good practice and critically examine different models of emerging thinking.

Drawing together this report involved a review of relevant published and unpublished material produced over the past decade. It is also informed by interviews and discussions with 'key contacts' – including policy makers, providers and older people concerned with the development, delivery and use of information, advice and advocacy. This approach helped in finding further references and resources; hearing first-hand accounts and experiences; building on ideas and case studies; and checking out models and meanings.

Having briefly outlined the context, this report will now move on to explore the meanings of information, advice and advocacy in relation to their definitions, principles, roles and relationships. There will then be a consideration of older people's perspectives and views on good services, and an analysis of policy and practice developments. This is undertaken in relation to each of five key themes that have strongly emerged within the literature and fieldwork:

- accessibility
- independence
- involvement
- strategy
- standards.

The report concludes with suggested priorities for further work in research, policy and practice.

## 2 UNDERSTANDING INFORMATION, ADVICE AND ADVOCACY

They [*information, advice and advocacy*] must move away from being seen as offering all things to all people, or from being seen as broadly offering the same thing. Older people need to know all about these services and what they can do.

(Older participant, Warwick)

### Defining information, advice and advocacy

Information, advice and advocacy could simply be defined in dictionary terms as follows.

- *Information*: the communication of items of knowledge, facts and ideas.
- *Advice*: an opinion or recommendation regarding a course of action.
- *Advocacy*: speaking up or pleading the case for.

However, in clarifying understanding of information, advice and advocacy, it is necessary to explore their meanings more closely

at a variety of levels and to discover some of the debates going on within and between them.

While outside the remit of this report, it is also worth noting that there is a need to define and differentiate information, advice and advocacy in relation not only to each other, but also to a range of other activities and arrangements. These include befriending, counselling, mediation, service brokerage and substitute decision making, all of which can otherwise overlap and obscure the meanings of information, advice and advocacy.

## Principles

Four common overarching principles are apparent within the literature on information, advice and advocacy. These principles are as follows.

- *Independence*: being independent helps to ensure that the needs and interests of the older person remain paramount. Clear conflicts of interest can arise where service providers also offer information, advice and advocacy relating to the services they themselves deliver.
- *Empowerment*: information and advice can help to ensure that older people are aware of their circumstances and options as well as the services and support they may require to take, and to remain in, control. Advocacy should enable older people to find and use their own voice wherever possible, as well as being about speaking up on their behalf if needed.
- *Inclusion*: information, advice and advocacy are ways of supporting older people to become involved in decision making and to be included in the life of the community.



Inclusion also means that these services should themselves be accessible and that older people should have equal opportunities to be involved in managing, developing and delivering as well as using them.

- *Citizenship*: older people may need to be informed, advised or represented in order to secure and exercise their rights and entitlements as citizens. This relates both to basic human rights and to consumer rights and entitlements to particular goods and services.

### **Forms of information, advice and advocacy**

Information and advice can be described in terms of *by whom* they are provided. This might be on a legal, professional (including welfare rights workers, health and social care professionals), voluntary or peer basis.

A detailed distinction can also be made between *impersonal* and *personal* types of both information giving and advice, according to *how* they are provided.

- *Impersonal* types include visual formats such as printed material, written enquiries, newspapers, computer access, web sites and displays; aural formats such as radio and audio tapes; and audio-visual formats such as television, video, film and information points.
- *Personal* types include aural formats such as telephone enquiries and telephone advice and information helpline services; and audio-visual formats such as mobile advice services, information fairs, information and advice services, and formal or informal personal contact.

However, these types of information and advice can of course be complementary:

Any of the more impersonal forms of information giving can be made more personal with the help of someone to explain or advise on the use of the material.

(Tester, 1992, p. 8)

Advocacy generally involves people making a case for themselves and advancing their own interests, or representing others and supporting them to secure and exercise their rights on an individual or collective basis. In recent years, there has been a burgeoning of self-, lay and professional forms of advocacy. This has been accompanied by a multiplicity of types and descriptions within literature and practice, including the following.

- Self-advocacy, which essentially means 'speaking up for yourself' to represent your own needs, wishes and interests.
- Collective advocacy, self-advocacy groups and organisations that provide mutual support, skill development and a common call for change.
- Peer advocacy takes place where one person advocates for another who shares a common experience, difficulty or discrimination.
- Citizen advocacy is a one-to-one, long-term partnership between an independent, unpaid 'ordinary person' and a disadvantaged 'partner'.

- Volunteer advocacy is independent and unpaid, but the advocate may work with a number of partners on a short-term issue or casework basis.
- Paid advocacy describes the role of advocacy workers who share the characteristics of volunteer advocates but are paid for the task.
- Professional advocacy may refer to the partial advocacy role of staff in health, social care and other settings.
- Public advocacy describes the activities of organisations that campaign on behalf of a particular group of people or collective issue.
- Legal advocacy, which is the most established and widely recognised form of advocacy and is undertaken by trained lawyers.

Further types of advocacy are described in terms of the following.

- Approach, e.g. personal advocacy and casework advocacy.
- Issue, e.g. complaints advocacy and hospital discharge advocacy.
- Condition, e.g. mental health advocacy and dementia advocacy.
- Capacity, e.g. instructed advocacy and non-instructed advocacy.

Self-, lay and professional forms of advocacy are frequently contested with regard to definition, principles and effectiveness (Dunning, 1998a; Atkinson, 1999; Henderson and Pochin, 2001). These critical debates are explored further throughout this report. However, within the kaleidoscopic array of 'advocacies', it is also important to recognise that older people might need different forms and types of advocacy at different times or indeed several at the same time.

## Roles and tasks

Information and advice work generally involves an information provider or adviser undertaking instrumental or 'doing' roles – by *giving* information and advice. They are most often about problem solving or are task centred in their approach.

While information work tends to be immediate or time limited, advice work can be relatively time consuming in guiding a person through a complex issue, situation or set of options (Tester, 1992; Tinker *et al.*, 1993; Harding, 1997).

Advocacy roles can be both instrumental and expressive. Essentially, this entails 'doing' by providing practical support or 'being' by providing emotional support, as shown below.

- 1 Instrumental advocacy roles:
  - representative
  - spokesperson
  - appointee, power of attorney, court of protection.
- 2 Expressive advocacy roles:
  - confidant/e
  - witness
  - enabler.

Advocacy relationships can take time to develop. Getting to know what is 'normal' for a person in need of such support may require a significant amount of ongoing contact before the advocate is in a position to effectively represent their interests or to enable the person to do so for themselves (Dunning, 1995; Murphy, 2001; Cantley *et al.*, 2003).

Information and advice can be undertaken through remote or impersonal formats, but advocacy very much depends on a 'face-to-face' relationship. There is no national advocacy telephone helpline, for example, yet this format is a common means of giving information and advice.

## **Linkages and relationships – a continuum or circles of support?**

As older people themselves say time and time again, there is a crying need for information and advice to help them think through the options that are available to them as their needs change ... Often there is a need for advocacy as well – for help and support to enable older people to assert their rights and gain access to what they need.

Harding (1997, p. 37)

Within the wider body of literature on information, advice and advocacy, there is much attention to the need for and provision of such services. However, there is little consideration given to the nature of the relationship between them.

Discussions with groups of older people in carrying out this review suggested that, in some circumstances, the relationship between information, advice and advocacy could be points or tiers along the same continuum. Indeed, there may be built-in

assumptions that this is the case in the development of policy and practice:

Information is what you need or want to know; advice is being guided as to how to go about things; advocacy is a way of acting on that information and advice to get your due.

(Older participant, Manchester)

Yet, the strongest proposition to emerge from older participants and officers throughout the fieldwork was that the link between information, advice and advocacy resembles interrelated circles, in which each links to the other. In such situations, rather than being different points along the same continuum, information, advice and advocacy may best be described as *circles of support*.

One such scenario is that of an older person at the time of hospital discharge when institutional care is being presented as the preferred option by staff and relatives. Advocacy may be required at the outset to help to obtain information on the full range of available services so that the older person is in a better position to reach a decision. Alternatively, the older person might have been advised to request the assistance of an advocate in order to support their right to take risks and return to live independently in the community. In neither instance does the older person necessarily start from the point of information before progressing on to advice and advocacy.

This more circular and seamless model of access and assistance accommodates both the needs of older people and the specific contributions of the services to best meet those needs. It may also help to engage those older people whom some studies suggest do not recognise the distinction between

information, advice and advocacy services or are even unaware of their existence in the first place (Quinn *et al.*, 2003).

## **Skills and services**

Information, advice and advocacy can all be viewed in terms of skills and services. A skill is the ability or expertise to inform, advise or advocate. A service refers to the organisational, agency or individual provider of information, advice and advocacy.

Health and social care professionals may have the skills to provide information, advise and indeed advocate. In fact, the use of such skills by professionals at the 'front line' of service delivery can be crucial in protecting a person's interests, at least at an early stage of an issue or problem being presented.

However, there are limits to the role as service providers where conflicts of interest arise or more specialist support is required. In such circumstances, it is imperative that the professionals concerned are aware and ensure that the person is referred on to an independent agency whose primary role is to provide an information, advice or advocacy service (Ivers, 1994, 1998).

Some skills might be shared across information, advice and advocacy services. Bateman (2000), for example, promotes a casework approach based on welfare rights information and advice work as a way of developing advocacy skills for health and social care professionals. Similarly, advocates might need to acquire skills as 'information aides' in order to support a person in obtaining relevant information, comprehending the content, considering the options and then acting on their decision (Dunning, 1995; Wertheimer, 1998).

## **Process of empowerment and social movement**

Information and advice services can be described as empowering in that they may provide an older person with greater awareness and understanding in order to direct their own actions and make decisions. Yet, within the literature and fieldwork, the role of advocacy as a process of empowerment is more strongly stated (Phillipson, 1990; Dunning, 1998a; Cantley *et al.*, 2003). Indeed, for some within the field of advocacy, this is a defining quality:

There is a real distinction between information and advice and then advocacy. I'm not here to give another service, I'm here to give a voice.

(Older advocacy worker, Manchester)

The issue of power also connects meanings of advocacy with older people to a wider social movement for human rights and representation. This connection significantly sets advocacy apart from being viewed simply as a skill or service.

The advocacy movement in the UK is made up of a number of disparate strands, with different histories, groupings and forms. It includes self-advocacy and peer advocacy as developed by people with learning disabilities, 'survivors' of the mental health system and councils of disabled people, as well as advocacy provided by professional 'allies' and citizen advocacy schemes across a range of user groups (Brandon *et al.*, 1995; Atkinson, 1999).

As the advocacy movement has grown since the 1960s, it has been associated largely with the activities and achievements of younger disabled people. Although older people have to some extent been represented collectively by pensioners' organisations and (latterly) older people's forums for over a century, advocacy by and for individual older people is a relatively recent endeavour.



The growth of local advocacy projects by and for older people since the late 1980s, together with the founding of the Older People's Advocacy Alliance (OPAAL) UK in the late 1990s, has opened up new opportunities for the definition and development of the older people's movement and the advocacy movement alike (Dunning, 1998a; Older People's Advocacy Alliance, 2002):

The pensioners' movement and the advocacy movement must work together in an organised way. Pensioners certainly have the experience and OPAAL has the expertise. Together that would be a wonderful combination.

(Helen Grew, Vice President, National Pensioners' Convention, speaking at the Independent Advocacy with Older People national conference, July 2002)

## **3 ACCESSIBILITY**

Older people view accessibility as being both a prerequisite and an indicator of 'good' information, advice and advocacy services. Accessibility may concern availability, awareness and appropriateness.

### **Availability**

The availability of information, advice and advocacy services is related to rights, recognition and resources.

Within a legal and policy context, information and advice are relatively well established and recognised sources of support. Legislation, such as the NHS and Community Care Act 1990, Disability Discrimination Act 1995, the Carers (Recognition and Services) Act 1995 and Health and Social Care Act 2001, has placed duties on health and local authorities to provide information. Policy developments have sought to augment the availability of advice as well as information services through initiatives such as the Community Legal Service, Patients' Advice and Liaison Services (PALS), NHS Direct and Care Direct pilots.

Voluntary sector providers such as the Citizens Advice Bureaux are also extremely well established, along with the information and advice services of voluntary organisations specifically for older people, including Age Concern and Help the Aged. They provide a range of services in a variety of personal and impersonal formats, including telephone helplines, web sites, written materials and face-to-face support.

On the other hand, the legislative and policy framework for independent advocacy is just beginning to develop, albeit in very limited circumstances. This includes the Health and Social Care Act (2001), which introduces a statutory right for all users of the NHS to access Independent Complaints Advocacy Services (ICAS); the support for the establishment of a range of independent advocacy schemes for people with learning disabilities (Department of Health, 2001); and the proposed introduction of specialist advocacy for people detained under reformed mental health legislation (Department of Health, 2002a).

In terms of present provision, the number of advocacy schemes for older people in the UK has risen steadily from about a dozen in the early 1990s to well over a hundred today. These schemes are run by a variety of agencies, from the statutory sector and voluntary organisations for older people, to independent advocacy schemes and organisations of older people. Some work with all older people, others are focused on a specific group, service or setting. However, this development is very patchy and there are concerns about, not only the limited quantity of advocacy schemes, but also the capacity and quality of what is available (Wertheimer, 1993; Dunning, 2000; Henderson and Pochin, 2001).

Moreover, despite the requirements placed on statutory authorities, the existence of information and advice services – as well as advocacy – can be seen to be vulnerable and lacking in variety when resources are restricted:

Information, advice and advocacy services tend to be seen as luxuries by funders such as local authorities – as not a real service and therefore less important when cuts are having to be made.

(Harding, 1997, pp. 37–8)

One-stop shops are fantastic for some older people, but there needs to be a choice. But will there be enough money for that?

(Older participant, Warwick)

## Awareness

In order for information, advice and advocacy services to be accessible, older people obviously need to be aware of their existence in the first place. Awareness of the presence and purpose of advocacy is generally acknowledged as being poor (Atkinson, 1999; Rai-Atkins, 2002; Quinn *et al.*, 2003), yet awareness of far more long-standing information and advice services has also eluded many older people (Lindow and Morris, 1995; Lord Chancellor's Department/Legal Services Commission, 2002):

You don't know what you don't know until you need to know it! We are awash with information and good advice, but most of the time it is like water off a duck's back ... until you need that piece of information or advice. That's when you should be able to find it but can't!

(Older participant, Rhondda Cynon Taff)

Advocacy services have to provide more information about themselves on what they do and what they are about. They have to break down barriers of ignorance before they can start work.

(Advocacy worker, Manchester)

Echoing the comments of Carter and Beresford (2000) regarding involvement, it is somewhat ironic that the language and meanings surrounding information, advice and advocacy can themselves serve to exclude older people:

Unless a person is very up on the language or is able to be very clear about what they want from where, they could end up being sent all over the place.

(Older participant, Warwick)

The situation can be compounded by the lack of awareness among front-line staff and senior professionals regarding the aims and availability of information, advice and advocacy services. (Tinker *et al.*, 1993; Ivers, 1994; Murphy, 2001):

Sometimes we [*older people*] end up telling them [*professionals*] what's going on.

(Older participant, Warwick)

The path to an advocacy scheme has many routes ... self-referral by older people, but mostly through care workers. But they don't always know about us.

(Advocacy worker, Manchester)

The following examples illustrate the development of inter-agency working and staff training as a way of improving the awareness of front-line staff and making services more accessible to so-called 'hard-to-reach' older people.

### **Inter-agency training in Liverpool**

The Health Benefits Initiative Team (HABIT), led by Age Concern Liverpool, has trained primary health care teams on welfare benefits and services, working with other agencies to enable older people to have more money, warmer and safer homes, and appropriate support to remain independent. It has also worked in surgeries alongside doctors actively encouraging patients to take up such services.

### **One-stop people in Rhondda Cynon Taff**

As part of a Better Government for Older People project to help older people access information and services, Rhondda Cynon Taff developed a network of 'one-stop people'. They included home care assistants and other staff, volunteers and older people who were trained to signpost and support older people in their work to seek out the information, advice and services they needed.

## **Appropriateness**

Appropriateness is about *how* information, advice and advocacy services are provided for older people. A number of studies reveal a lack of appropriate information and advice services across a range of different social groups, services and settings. These include older people from black and minority ethnic groups (Dunning, 1998b; Department of Health, Social Services Inspectorate, 1998a); older people in rural areas (Department of Health, Social Services Inspectorate, 1999); older people with dementia and mental health problems (Audit Commission, 2000); carers (Phillips *et al.*, 2002); and older people seeking specialist advice on housing options (Age Concern/The Housing Associations Charitable Trust, undated):

How do older people get access to information and advice on housing ... not just sheltered housing but housing like everyone else?

(Older participant, Rhondda Cynon Taff)

The literature and fieldwork also highlight the problems and pitfalls of over-reliance on a single format or type of information giving and advice. The limitations of leaflets and written materials are well documented (Payne *et al.*, 2000; Quinn *et al.*, 2003). The

rise of e-government and assumptions about a society of 'silver surfers' easily accessing information and advice by means of ICT have also been subject to critical reappraisal (National Audit Office, 2003a; Pilling *et al.*, 2004; Sourbati, 2004).

In the face of these failings, older people's views on what makes more appropriate provision of information and advice services are well known and frequently revisited within the literature. Over a decade ago, Tester (1992, p. 19) identified a number of already 'well-established conclusions' with regard to information provision, including the following.

- Information should be targeted to specific groups of the population and various sub-groups among the older population.
- Information should be targeted to a specific geographical area.
- The content and form should be appropriate to the group for which that information is produced.
- Information must be widely accessible and made available at the right time, at critical points in people's lives.

More recently, Carter and Beresford (2000, p. 26) highlighted research into the views of older people, which suggested that, in order to be helpful, information should:

- 1 be of immediate relevance, clear, attractive and brief
- 2 be appropriate to people's abilities, experience, knowledge, language and culture

- 3 take account of the particular needs of:
  - members of minority ethnic communities
  - people with limited mobility
  - people with sensory impairments
  - people with limited literacy skills
- 4 link verbal and written information
- 5 be available from clear contact points.

In essence, therefore, older people want a variety and choice of personal and impersonal formats of information and advice. They also want services that are diverse in their focus, providing generic as well as specialist support throughout the life course. Another consistent message is that face-to-face contact is a particularly highly valued and effective form of communicating information and advice.

### **Improving the impersonal – written formats in Kensington and Chelsea**

The Kensington and Chelsea Readers' Group was established by the local authority as part of its Better Government for Older People project to produce more accessible written information. The Group was made up of a diversity of older people who reviewed and commented on information materials for publication. It grew because of the demands of more older people to get involved and more bodies wanting to benefit, including health trusts, voluntary organisations and London Transport as well as the local authority on a wide variety of topics.



### **Making the impersonal personal – one-stop shops and ICT in Warwick**

The Kenilworth Connection in Warwick District is a one-stop shop that provides information on a range of services, groups and activities in the area. It does so by means of written materials, ICT and face-to-face contact. Also in Warwick District, the Leamington Elders Action Project (LEAP) brings together personal and impersonal formats as a group of older people helping community projects through the provision of information, advice and training in computer skills, web-site design, video production, presentations and newsletters.

### **The Camden life course approach**

The London Borough of Camden has developed a quality of life strategy for older citizens (2002). The strategy aims, not only to make older people aware of a range of opportunities that facilitate health and well-being and to ensure that they have equal access to a range of services and resources, but also 'to prepare generations for the opportunities and challenges of later years'. The varied ways in which Camden has sought to undertake its information and advice work includes briefings for employees of all sectors and the development of a later-life pack. It has also further developed groundbreaking staff guidance on communication with older people (initiated by the Camden and Islington Health Improvement Programme, 2001).

The appropriateness of how advocacy is provided is documented less extensively than information and advice, but is similarly concerned with form and focus.

Various *forms* of self-, lay and professional advocacy may each have something to offer an older person at some time or at the same time. While it is crucial to support self-advocacy and ensure

that the direct voice of the older person is heard if at all possible, this should not preclude other forms of representation. Everybody may need somebody to speak up alongside or on behalf of them on an individual or collective basis.

This point is presented pertinently by Helen Grew, Vice President of the National Pensioners' Convention, at a recent advocacy conference:

Peer involvement, bringing shared attitudes and experience, could be helpful. Older people who might have advocated in different ways in the past might be more acceptable to their peers. Yet younger people would bring a fresh perspective. The main thing is of course to be a good advocate.

(Older People's Advocacy Alliance, 2002, p. 3)

What really matters here is having the choice between different forms of advocacy that are both principled and effective when needed. This should not be lost in contested debates about 'true' advocacy (Dunning, 1998a; Atkinson, 1999; Henderson and Pochin, 2001).

In terms of *focus*, the literature and fieldwork suggest that the development of advocacy with older people should include generic and specialist services. In common with information and advice – but in a far less developed field – more advocacy services are required to take account of the needs of particular groups of older people (Dunning, 1998a; Rai-Atkins, 2002; Cantley *et al.*, 2003).

The main *advantages* of *generic* schemes can be as follows.

- They may provide a 'one-stop shop' for rights and representation of citizens within a diversity of social groups, settings and situations.

- They may avoid replication of service categories through which older people and other groups might fall.
- There are opportunities to share a range of knowledge, skills and resources within the scheme.
- Specialisation can be developed under its umbrella.

The main *disadvantages* of *generic* schemes can be as follows.

- Older people may become subsumed under work with other groups.
- Older people may overlook the scheme as an obvious source of support.
- The scheme might become a 'catch all' without adequate resources to meet the needs of a diversity of older people and other groups.

### **A generic scheme – Warwickshire Independent Advocacy Alliance**

Warwickshire Independent Advocacy Alliance is run by a management committee that involves service users, representatives of voluntary organisations and independent individuals. The scheme provides different forms of advocacy with younger adults with physical disabilities, learning difficulties and mental health problems as well as with older people. Advocacy is undertaken in a range of institutional and community settings and situations.

The *advantages* of *specialist* schemes can be as follows.

- Developing knowledge and skills in work with a specific group, setting or situation.
- Concentrating resources on a 'hard-to-reach' group or hard-to-resolve situation.
- Raising public awareness and the profile of advocacy with older people.

The *disadvantages* of *specialist* schemes can be as follows.

- Less opportunities to share knowledge, skills and experiences of cross-cutting issues, for example, mental capacity and consent.
- Lack of development on the part of other organisations and schemes.
- Competition for resources with other schemes.
- Danger of fragmentation rather than diversification of advocacy at local level.

### **A specialist scheme – the Beth Johnson Foundation Dementia Advocacy Project**

The Beth Johnson Foundation Dementia Advocacy Project evolved from a long-running citizen advocacy project established in 1989. The new project was set up in 1998 to be simultaneously a local resource and a wider demonstration project around advocacy work with people with dementia. The project has a paid advocacy co-ordinator and support staff. It has been subject to external evaluation (Murphy, 2001) and continues to develop in key areas of practice, including communication, mental capacity and awareness raising.

## **4 INDEPENDENCE**

Independence is a key shared principle of information, advice and advocacy. It is in itself viewed as being an indicator of a 'good' service by older people. Within the literature review and fieldwork, older people highlighted the importance of independence to ensure that their interests remained paramount. Concerns are also raised that conflicts of interest are inherent where service providers offer information, advice and advocacy, and deliver direct services (such as accommodation, day care, domiciliary help, insurance and transport) themselves.

### **Independence – needs and challenges**

In its report on the health and social care priority needs of older people, the Health and Older People (HOPe) Group highlights the way in which older people themselves value information, advice and advocacy services. The Group emphasised the essential nature of independence in these services for older people in order to:

... promote their autonomy, to enable them to access appropriate services, and to protect their interests and wellbeing.

(HOPe Group, 2000, p. 9)

Similarly, older people view information, advice and advocacy as essential components of support for effective involvement. For such support to be really helpful, there is a need for independence:

... separate from service agencies and providers and not tied up to their values and assumptions.

(Carter and Beresford, 2000, p. 26)

These findings were echoed in discussions with older people in the production of this report:

Independence is really crucial for the most vulnerable. That is because reluctance to ask for something or even complain is inversely proportionate to helplessness.

(Older participant, Warwick)

My fears are allayed when I know that you're not answerable to the [*service*] providers or the family or whoever, but to the person and the agency which is independent.

(Older participant, Rhondda Cynon Taff)

The way in which the organisational preoccupations and imperatives of providers can get in the way of meeting the needs of older people is highlighted in a number of studies. One example of this is a study carried out in Wales, in which older people found that information provided by local authorities was largely about local authority services themselves, rather than the range of other services and providers in the locality. Moreover, they reported that there was little or no published information on important but

potentially sensitive matters such as charging policy, eligibility criteria and service availability (Adams, 1997). More recent research reveals that deficits in the provision of such crucial information, advice and guidance on services for older people persist in some areas (Quinn *et al.*, 2003; Audit Commission, 2004a, 2004b).

The consequence of the absence of independence was felt keenly by a number of older people who participated in the fieldwork for this report. In one case, hospital discharge proved to be a particularly testing time:

The professionals will say it is good for older people to have services to help them to make informed choices, offer good advice [*and*] represent their views. But, if people are not getting out of hospitals quickly enough or not being happy with what they are given, they come down like a ton of bricks. That's where there is strength in independence.

(Older participant, Manchester)

Independence does not only challenge the 'in-house' information, advice and advocacy services of statutory organisations, it also poses pertinent questions for voluntary organisations that provide direct services as well as information, advice and advocacy services. The role of large voluntary organisations and local groups was the subject of a number of older people's concerns about independence:

The 'business' of voluntary organisations for older people needs to be challenged. What or who are they really there for?

(Older participant, Camden)



They [*a voluntary organisation*] provide information and advice and the day centre and they run home helps. But what if they get any of it wrong? Where do we go then?  
(Older participant, Manchester)

Independence is also a potentially uncomfortable issue to address within smaller community organisations. These may include organisations run by and for older people from black and minority ethnic groups that are in the position of providing a range of direct services as well as information, advice and advocacy within a particular community. The dilemma was recognised by a member of an Asian community organisation during the fieldwork:

For a small black or Asian organisation, it is very difficult to compartmentalise information, advice and advocacy from other things. We must remain approachable and people come in for many things.  
(Asian community worker, Manchester)

## Conflicts and compromises

A number of compromises towards an ideal or rigid stance on independence were advanced during the fieldwork. While it was recognised and strongly expressed that there was no real substitute for the availability of truly independent information, advice and advocacy services, the significance of independence was seen to depend on the following.

- The nature of the issue – whether there is a conflict of interest with the aims, activities and services of the organisation.

- The integrity and insight of the staff – whether officers are trusted, aware and able.
- The safeguards put in place within the organisation – whether the information, advice and advocacy services can operate freely and remain unfettered by the wider organisation.
- The protocols put in place with relevant agencies – whether the organisation had established mechanisms to refer out to an independent body if conflicts of interest arose.
- The lack of choice – whether there were any independent agencies to provide alternative assistance in the area.
- The commitment of the organisation towards developing independent services – whether the organisation itself was providing information, advice and advocacy services as a first step towards the development of a truly independent agency.

The following example demonstrates the way in which voluntary organisations attempting to provide information, advice and advocacy as well as direct services for older people can resolve the conflict of interest question conclusively and with integrity through the development of a distinctive service.

### **Birmingham Citizen Advocacy**

Birmingham Citizen Advocacy was set up initially by Birmingham Association for Mental Health (Birmingham MIND) in the late 1980s as a pilot project to provide advocates for people with mental health problems being resettled from long-stay hospitals. The organisation was itself a provider of

residential care and a range of other direct services. An independent management committee for the advocacy project was quickly established, comprising lay people, professionals and representatives of patients' groups and other interested bodies. The new organisation became a registered charity and a limited company. Since the early 1990s, Birmingham Citizen Advocacy has been able to develop specialist independent advocacy services with older people with dementia, Asian older people and people with hearing impairments.

## **Independence and interdependence**

A final consideration in exploring the nature of independence is that it need not and should not entail splendid isolation. Independence and interdependence can co-exist. In order to best serve the interests and wishes of older people themselves, information, advice and advocacy services should establish a range of relationships, protocols and partnerships with other organisations – a point that is revisited in relation to strategy later in this report.

This is essential with regard to issues such as adult protection and elder abuse (Department of Health, 2000), in which advocacy schemes are a key component of the multi-agency response. It is also useful in simply being able to share knowledge, expertise and practical help within local networks. This was best captured in the following comment about advocacy, but the message is applicable also to information and advice:

Independent in representation, interdependent in terms of resources.

(Project worker, Manchester)

## **5 INVOLVEMENT**

Within the literature review and fieldwork, older people view 'good' information, advice and advocacy services as being those that involve them. Such involvement reflects the principles of empowerment, inclusion and citizenship being put into practice. Furthermore, good services are seen to become better by the involvement of older people (Better Government for Older People, 2000a; National Audit Office, 2003b; Audit Commission, 2004a, 2004b). Involvement may take place at three levels – personal, organisational and policy.

### **Personal**

At a personal level, older people see it as important to be engaged in the process of information giving, advice and advocacy if they are able to do so. This means the individual older person being directly involved in seeking information, determining options, making decisions and advocating for themselves wherever possible. For providers, this requires an enabling approach – developing trust, confidence and skills with the older person where needed (Carter and Beresford, 2000):

Any worker from an advice or advocacy bureau should have clarified their role at the start. I would think it is the job of the worker to help me to find things out and represent my own wishes. They shouldn't close me down

or shut me out ... I'd want to be there up with the adviser or the advocate – in control of my situation.

(Older participant, Rhondda Cynon Taff)

Failing to engage older people in these processes can lead to the creation of a layer of dependency and further disempowerment (Dunning, 1998a). This can be an unintended but nevertheless damaging consequence of trying to give a service rather than enable an individual. It is an inclination of providers recognised by older people and perhaps best described as being, 'the myopia of therapeutic good intention' (Jack, 1995).

There is a tendency for traditional health and social services and others to be giving help, advice or whatever to older people. The attitude follows the language. Information, advice and advocacy services should try to facilitate us to make choices to enable us to have a good quality of life.

(Older participant, Camden)

A further benefit of involving an individual older person within the information, advice or advocacy process is that it can potentially lead to greater involvement in the life of the community. In this regard, involvement could be an outcome of, as well as a process within, information, advice and advocacy:

Once I had made sense of it all and got things sorted out for myself [*the use of a library computer information system and internet*], I thought about those who hadn't. Now I make sure I explain it to people at every opportunity. I say that, if I can understand it, then you can.

(Older participant, Warwick)

**The planning for a healthier retirement pilot project:  
Beth Johnson Foundation, Stoke-on-Trent**

The Beth Johnson Foundation was one of eight pre-retirement pilot sites in England established on behalf of the Department of Health in 2001 to test different ways of providing advice services for people approaching retirement. The initiative formed part of the programme of the Older People's Task Force, with an emphasis on standard eight of the National Service Framework for Older People.

The focus of the work in Stoke-on-Trent was to reach people in neighbourhoods and communities of interest, and to develop a pack for use by trained volunteers aged 50+ acting as lay health advisers for their peers. Older people involved at an early stage of the project pointed out that 'you don't know what you don't know' and identified a range of critical life course related topics to be considered. This work is now being further developed post the pilots as a training tool that includes physical health, mental well-being, family and relationships, leisure time, housing, finance and employment.

## **Organisational**

At an organisational level, older people can benefit from services to which they have themselves contributed. While there is a symbolic significance in involving older people in the management and running of services intended for themselves and their peers, there is also a profoundly practical purpose. This finds expression in the lyrics of Leadbelly via Brandon *et al.* (1995, p. 103):

It takes a man [*or indeed a woman*] that has the blues, to  
sing the blues.

Many older people bring knowledge, skills and first-hand experience – personal and professional – to the work of organisations providing information, advice and advocacy services. But, although the benefits of this are well established, there remains a great deal more potential to be released and opportunities to be realised (Harding, 1997; Better Government for Older People, 2000a, 2000b, 2000c; National Audit Office, 2003b; Audit Commission, 2004a, 2004b).

When we founded the service, we had our priorities at the ready. Not all embracing, not too restricting. We knew our people. We had all been organisers and doers all our lives. We were free to get on with it.

(Older participant, Manchester)

Many older people depend on other older people like us to get things going and take it to them. If there's no one here like us doing it, they won't get what they want. There are more of us out there who could make a go of things – with a bit of help and encouragement.

(Older participant, Rhondda Cynon Taff)

However, the fieldwork revealed among older people some concerns that are rarely recognised in the literature on involvement. These largely surrounded accountability, quality and confidentiality. More explicitly, there were concerns that older people:

- working in the name of their peers should be closely accountable to them

- should expect a good standard of service whether provided by professionals or peers
- should feel comfortable that personal information, such as financial and health matters, would be treated in confidence by projects involving peers, particularly in small communities.

### **Manchester Link-Age**

Link-Age is an advocacy and information support project for people aged 55+ in North Manchester. The project is funded currently by North Manchester Primary Care Trust. It is managed by a committee of older people who employ a development worker. The project also has volunteers to help provide advocacy and administrative assistance.

The stated objectives of the project are to enable older people to make informed decisions about any choices they have to make and to be able to communicate their views effectively; and that older people have the right to the support of an independent advocate to ensure that their own desires and interests are taken into account.

The project has built up considerable information resources on health and social services policy and provision. It is also an active member of the local Elders' Forum and Manchester Alliance for Community Care, which helps it to keep it in touch with the views of a wider constituency of older people and trends in social policy and advocacy.

## **Policy**

As well as older people being involved in the running of information, advice and advocacy organisations, there are real benefits to their involvement at a policy level in shaping strategies and services. The engagement of older people as partners in policy



making beyond limited consultation optimises their contribution, as well as improving the quality of information, advice and advocacy services themselves (Better Government for Older People, 2000a, 2000b, 2000c; National Audit Office, 2003b; Audit Commission, 2004a, 2004b).

Older people were involved in developing the corporate report on information and advice in Camden. How we went about it and being part of it is why it says what it says. You can tell.

(Older participant, Camden)

Furthermore, the improvement of information, advice and advocacy services through the involvement of older people at a policy level can bring about positive development in other services too:

We were involved in planning the project to produce better information and advice for older people, but it has had a much wider impact on other services too. If we were better informed, then the services had to be prepared for us. Everybody can see our A–Z of services and there is greater recognition of the importance of information to older people because of our involvement.

(Older participant, Rhondda Cynon Taff)

### **London Borough of Lewisham**

Lewisham has a long tradition of supporting the involvement of older people and encouraging the representation and contribution of older people in the business of the local authority. Since 1986, Lewisham Pensioners' Forum has been funded by the Council and, along with other older people in the borough, has been involved in policy development with the Council.

*continued overleaf*

Lewisham Council recognised the importance of information in the recent development of its multi-agency strategy for an ageing population – itself shaped by the involvement of older people. The dissemination of useful and relevant information was seen to be a key part of the strategy to enable older people to play a full and active part in the community. Older people have also been involved in a number of practical initiatives, such as the production of a 'Pensioners' Directory' that is available in a variety of formats.

## 6 STRATEGY

The need for a more strategic approach has been highlighted across a range of services for older people (Benington, 1997; Better Government for Older People, 2000a; Audit Commission, 2004a, 2004b). In present policy terms, more integrated, co-ordinated and citizen-centred strategies and services necessitate a more 'joined-up' approach by policy makers, planners and providers.

A key lesson of the Better Government for Older People (BGOP) national programme was that:

Joined up policies and planning are required for more joined up delivery on the ground ... Furthermore, this integration needs to be 'vertical' (between different tiers of government) as well as 'horizontal' (between different services and stakeholders).

(Better Government for Older People, 2000a, p. 104)

With regard to information, advice and advocacy services, older people are similarly concerned that there should be a strategic approach that is better integrated, co-ordinated and citizen-centred (Tester, 1992; Better Government for Older People, 2000a; Audit Commission, 2004a, 2004b). This message was made explicit by older people in the fieldwork and was seen to profoundly affect the way in which information, advice and advocacy services were provided.

The more and better it will be if everyone pooled their resources and worked together.

(Older participant, Warwick)

The biggest task is connecting all the organisations. People within the government departments and the statutory services seem to struggle to pull together themselves. People in the community just bump along between them.

(Older participant, Warwick)

## **Benefits of a strategic approach**

The main benefits of a strategic approach to information, advice and advocacy services for older people are:

- better accessibility for older people through better co-ordinated and integrated services
- better informed providers of services (including services run by and for older people) who are accordingly more able to meet older people's needs themselves or to make more appropriate referrals to other agencies if necessary
- better use of available resources through identification of gaps and areas of duplication
- better informed, targeted and sensitive commissioning
- better joint working across other areas of policy and provision.

On this final point, the experience of information and advice projects initiated by BGOP was that they proved to be an excellent focus for joint working across different agencies to create a 'concrete product' and a fillip for further partnership working. Information and advice was also found to be a good corporate theme within local authorities and other organisations (Better Government for Older People, 2000a, p. 43).

**Rhondda Cynon Taff**

The Rhondda Cynon Taff Better Government for Older People pilot project aimed to build an integrated network to help older people access information and services from provider agencies and to develop a strategy to deliver co-ordinated support services to older people through a range of complementary community-based supports. This involved a partnership of the local authority, health agencies, voluntary organisations, a university and older people's forums.

A range of innovative methods were used in inter-agency work alongside older people. This included secondment of staff for the Pensions Service (formerly the Benefits Agency) to the local authority; sharing of information between agencies and targeting households where there had been no take-up; simplification of benefits forms; production of a comprehensive handbook of services; as well as the use of 'one-stop people'.

The project has had positive practical results but has also brought about improvements at strategic level for the partner agencies and older people. They have all had to work together to develop the policies and protocols to make it happen. The local welfare benefits work is now being rolled out nationally while, in Rhondda Cynon Taff itself, the strategy and information network continues to develop.

## **Government initiatives on information, advice and advocacy**

In recent years, the Government has initiated a number of significant developments in policy and provision of information, advice and advocacy services. These include Patients' Advice Liaison Services (PALS) and Independent Complaints Advocacy Services (ICAS) as part of the reforms of the NHS, as well as the piloting of Care Direct and the more recent launch of the Link-Age Service, as briefly outlined below.

- *Patients' Advice and Liaison Services:* PALS are an essential component of the new system of patient and public involvement unveiled in the NHS Plan. The first wave of pathfinder PALS were operational in April 2001 and used to inform their subsequent development and standards. PALS aim to provide service users, carers and families with on-the-spot help and accurate information about the Trust services and other health-related issues, as well as support to resolve concerns quickly and effectively within the Trust. PALS are also intended to act as a gateway to independent advice and advocacy support from national and local sources, including ICAS.
- *Independent Complaints Advocacy Service (ICAS):* ICAS is similarly a part of the patient and public involvement agenda within the 'new' NHS. ICAS is intended for anyone wishing to make a complaint about local NHS services. ICAS provides free independent confidential support, including, information about complaints procedures; assistance in letter writing; support at meetings; as well as listening and acting on behalf of patients. ICAS is an independent body

whose role it is to advise and help people who have a complaint about local health services. Primary Care Trust (PCT) Patients' Forums commission and/or provide ICAS for their local population. The Commission for Patient and Public Involvement in Health identifies quality standards, sets criteria for provision and provides national assessment.

- *Care Direct pilot projects*: the Care Direct pilot projects were established by Government to provide older people and carers with information about, and access to, social care, health, housing and social security. They were launched in 2001 with six pilots in the South West of England. Two further phases were planned, with a nationwide roll-out by 2004. It was intended to be made up of a telephone helpline staffed and managed by NHS Direct call centre staff and, in each local authority area, a local help desk and assistance provided by 'volunteer befrienders' and access to independent advocacy if needed. There was also a Care Direct web site as an alternative means of obtaining information and advice.
- *Link-Age*: the Government declared its intention to build on Care Direct with the recent launch of Link-Age, led by the Department of Work and Pensions. The Link-Age initiative aims to bring about closer working between the local Pensions Service offices, local authorities, voluntary organisations and others for a more joined-up service for older people. This is intended to further help older people to access a range of services, departments and agencies from a single point of contact; make informed choices and decisions; and promote and support their independence.

## Issues arising from government initiatives

Fundamentally, the above initiatives are concerned with better informed, advised and represented users, and more citizen-centred services. However, in terms of vertical and horizontal integration – or how ‘joined up’ they are between Government and the grass roots, and across different services and stakeholders nationally and locally – the following issues arise.

- *Joined-up legislation and policy:* there are challenges in joining up across Government and within departments in the development of information, advice and advocacy at a legislative and policy level. Prompted by the National Service Framework, there is now an information strategy for older people pulling together health and social care in England (Department of Health, 2002b), yet there is no such strategy for advocacy. The advent of Link-Age has not addressed this relative invisibility. Older people have the right to access ICAS as patients of the NHS and the provision of advocacy is being advanced within reforms for people with mental health problems and people with learning difficulties. However, this might best be described as piecemeal policy making, which denies older people and other groups the right to independent advocacy when such support might be needed.
- *Definition and development:* top-down legislative and policy initiatives can distort the definition and development of information, advice and advocacy services at the grass roots. The relatively high recognition and resourcing accorded to ICAS, for example, may serve to stunt the development of other forms of independent advocacy or skew the focus of such support at local level. Similarly,



some information and advice providers report threats to their funding during the piloting of Care Direct:

When local authorities need to cut budgets, and they see a new service being set up ... which they are partly funding and which describes itself as information and advice for older people, then funding for voluntary sector information and advice services can be a target.

(Voluntary sector officer)

- *Independence and interdependence*: there is a need for greater clarity about the principle of independence and the nature of interdependence within the new sets of relationships created by these initiatives. PALS exists as an 'in-house' information and advice service within the NHS, whereas the running of ICAS is seen to be a step removed from the health-care providers. Learning from the experience of the Care Direct pilots, Link-Age must balance the need for a high degree of independence within information and advice services alongside the essential interdependence inherent within its partnership approach.
- *Aims and activities*: the aims and activities of existing services and sources of support should be clearly understood and mapped out to address duplication and deficits at local level. Careful consideration may be needed with regard to the roles and tasks actually being undertaken. The title 'volunteer befriender' as used within the Care Direct pilots, for example, was misleading when the role was short term, specific and more akin to outreach information and advice work. Similar concerns had been raised with regard to the advent of PALS, which began life

as the Patient *Advocacy* Liaison Service during the pathfinder phase. Its recasting as *Advice* made a difference in terms of both public perception and the nature of service provision itself.

- *Time and capacity*: time and other resources need to be invested by stakeholders especially at the early stages of agreeing core principles, engaging a diversity of older people at the outset, developing the partnerships, and putting protocols and processes in place for joined-up strategies and services. An adequate period of time for learning from pathfinders and pilots also needs to be built into the targets and timescales set for such initiatives.

Furthermore, information, advice and advocacy services at a grass-roots level must have sufficient capacity to meet the expectations of essentially 'top-down' initiatives. Wrongful assumptions can be made that, for example, independent advocacy services are readily available to absorb referrals from PALS, ICAS and the developing Link-Age initiative, when the reality is that there are insufficient resources or schemes to meet present demand:

What is not seen by everybody is the protocols developed to get it all going. There is a process we have gone through to bring about changes. This has wider ramifications. Some departments left it for others to get on with. They took a while to get on board and see it involved them. More older people need to be involved in all this to make sure things continue to improve in the same way in all [service] areas. This takes time to do properly.

(Older participant, Rhondda Cynon Taff)

## **Requirements for a strategic approach**

Given the potential benefits and barriers to 'joined-up' working at all levels, and the particular experiences of BGOP, the Audit Commission and government initiatives such as PALS, ICAS and the Care Direct pilots outlined above, the main requirements for a strategic 'joined-up' approach towards information, advice and advocacy services for older people can be summarised as being:

- development of shared vision and values
- clarity of principles and approaches
- understanding of one another's aims, organisation and activities
- mapping what already exists, what works and identifying the gaps
- developing joint policy, protocols and practice as appropriate
- building capacity of grass roots to contribute and meet commitments
- engagement of older people at all levels
- training and awareness of 'front-line' staff
- commitment of decision makers at a senior level to make it happen.

### **A tale of two PALS**

Pensioners' Advocacy in Lewisham Scheme (PALS) was established in the early 1990s by members of Lewisham Pensioners' Forum who were concerned that their more vulnerable peers, particularly those in institutional settings, needed independent advocacy. The scheme has been run by and for older people, and has provided a consistent and committed advocacy service on a shoestring budget. A decade on, the scheme continues to provide powerful peer advocacy, but has received little of the recognition and resourcing required to develop its capacity within the present policy context. Indeed, in 2003, the scheme had to change its name to Lewisham Independent Pensioners' Advocacy (LIPA) because of the advent of the Patients' Advice and Liaison Services (PALS) in the 'new' patient and public involvement orientated NHS.

## 7 STANDARDS

Older people are increasingly being acknowledged as a major 'stakeholder' group in debates about quality standards and services within research (Henwood *et al.*, 1998; Qureshi and Henwood, 2000). The older people involved in the fieldwork for this report were clear that 'good' information, advice and advocacy services intended for them should be of an acceptable, consistent and recognised standard:

The last thing you need if you need information, advice or advocacy is a bad service.

(Older participant, Warwick)

There should be proper standards for the services and properly trained up staff. It should not be left to chance or up to individuals to do badly or well in each local area.

(Older participant, Warwick)

People could be in a vulnerable state when they seek this support. They could be getting wrongful information and advice. The staff might be speaking over them, not together with them. But there is no comeback if you don't know what it is you should be having.

(Older participant, Warwick)

## **Present standards**

Quality standards are generally well defined, established and recognised for information and advice services. A number of organisations providing information and advice, including the National Association of Citizens Advice Bureaux, Help the Aged Seniorline and Age Concern Information and Advice Services, have developed their own 'in-house' quality frameworks and standards. Registration, accreditation or membership of external bodies including the National Telephone Helpline Association, Advice UK and the Federation of Independent Advice Centres is also relatively widespread.

In 2000, the Government launched the Community Legal Service (CLS), with the overarching purpose to ensure that people can easily get the information, advice and assistance they need with legal problems at an early stage. It was established because of recognition that there was a lack of co-ordination, of referrals between providers and of consistent quality standards. CLS partnerships have been established to improve co-ordination, planning and networks at local level and a CLS quality mark accreditation scheme has also been developed (*Community Legal Service Partnerships News*, 2002).

### **The CLS quality mark**

The CLS quality mark accreditation scheme encourages referrals and enables different types and levels of provider to demonstrate stringent standards laid down. Any provider wanting to be part of the CLS and display the CLS logo must achieve the minimum standards under the CLS quality mark. It is intended that users who go to CLS providers feel confident of receiving a service that meets an agreed minimum standard and providers can feel confident in referring or signposting to a CLS quality marked organisation.

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The different levels of the quality mark are information, general help and specialist help. An inclusive quality project has been established by the CLS in order to help small community-based groups to obtain the CLS quality mark. This specifically includes community organisations providing information and advice for older people.

If you offer advice and send someone to another agency you should follow up and see if it worked and what they got as part of ensuring quality. As part of the protocol you must agree that, if you refer people on and signpost them to another service, you must follow up and see how they got on.

(Older people's project worker, Manchester)

In contrast, there has been limited recognition, consistency or ownership of standards in advocacy. Indeed, it is notable that, while providers of mediation services successfully developed a distinctive quality mark alongside those of information and advice providers as part of the CLS initiative, as yet there is no such symbol specific to advocacy.

However, there have been a number of initiatives to create, complement or otherwise contribute to the development of 'good' generic and specialist advocacy services. These include:

- advocacy charters (Advocacy Across London, 2000)
- codes of practice (United Kingdom Advocacy Network, 1997; Barnes *et al.*, 2002)
- evaluation tools (Hanley and Davies, 1998)
- training programmes (Brooke and Harris, 2000).

Yet, few of these developments have been specific to advocacy with older people (Wood, 1991; Dunning, 1995; Older People's Advocacy Alliance, 2002).

## **The benefits of standards**

The literature review and fieldwork highlighted a number of potential benefits in the development of standards for information, advice and advocacy services. The following are seen to be the most important of these benefits.

- *Effectiveness*: standards can provide a benchmark for quality from which to measure performance and evaluate the service.
- *Accountability*: standards can enhance public confidence, recognition and transparency of the service.
- *Protection*: standards can help to safeguard the interests of potentially vulnerable people against a bad service and protect the integrity of the service itself.
- *Clarity*: standards can help users, funders, commissioners, evaluators and others know what to expect from the service:

We need a recognised definition of advocacy to measure what we are doing ... a more professional approach ... and a move towards proper training and mechanisms.

(Older participant, Manchester)



A one-stop shop is needed for the Sikh community. The community has been doing it unofficially but, if it goes wrong, there may be detrimental consequences. There needs to be a more professional approach.

(Asian community worker, Warwick)

## **The challenges of standards**

Despite the clear benefits outlined above, a number of challenges have emerged in the development of standards for information, advice and advocacy services. Standards are particularly keenly contested within the advocacy movement, a discourse described by one grass-roots advocacy activist as being 'The Great Standards Debate'.

The most acute tensions and issues appear to be concerned with principles and effectiveness; process and outcomes; costs and benefits – and to rest within the key question of who sets the standards.

### ***Principles and effectiveness***

A key concern about standards is the extent to which they might diminish or even destroy the core principles, values and spirit of information, advice and – especially – advocacy services (Henderson and Pochin, 2001). For some, the introduction of standards heralds a move into the mainstream and a loss of flexibility and innovation:

We turn into just another service.

(Older advocate, Manchester)

Yet, the fieldwork revealed that there is a growing realisation that standards matter and that there has perhaps been an over-idealisation and a denial of shortcomings in some services:

There is no argument against standards ... We need to show that our [*information, advice and advocacy*] services work. It is not good enough to demonstrate adherence to principles alone. In fact, we need to go beyond setting standards to assessing service quality.

(Older people's community worker, London Borough of Camden)

In this respect, the challenge is to develop standards for 'good' information, advice and advocacy services that underpin rather than undermine the core principles and values while capturing the quality of their work:

Both principle and effectiveness need to be saved.

(Management committee member of national older people's advocacy organisation)

### **Scottish standards**

In Scotland, the advocacy development organisation Advocacy 2000 produced a *Key Ideas on Independent Advocacy* pack following a national consultation exercise that involved a wide variety of people and projects providing advocacy services. The pack pulls together generic principles and practice to capture both ethos and effectiveness for a range of forms of advocacy. This work subsequently informed the Scottish Executive guide for commissioners in Health Boards, NHS Trusts and local authorities, as well as a number of other developments nationally (Advocacy 2000, 2000; Scottish Executive, 2000).

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In 2003, the Advocacy Safeguards Agency (ASA) was launched with funding from the Scottish Executive Health Department to 'make sure that good quality independent advocacy is available to anyone in Scotland who needs it'. The main functions of the ASA are to:

- assist health and local authority commissioners to develop independent advocacy across Scotland and across all health and social care groups
- ensure, through evaluation, that the principles, practice and outcomes of the work done by advocacy organisations are meeting the needs of the people who use them
- develop policy and good practice in relation to independent advocacy across Scotland
- research matters relating to independent advocacy and, in particular, the effect of independent advocacy on the lives of people in Scotland.

### ***Process and outcomes***

While the measurement of standards can sometimes be weighed towards outcomes, process can be crucial in capturing older people's perceptions and experience (Williams, 1998; Qureshi and Henwood, 2000). Some older people in the fieldwork were direct in their desire to achieve a specific outcome:

I don't mind who or what it [*the service*] is like, as long as I get a result.

(Older participant, Manchester)

When you talk to some older people, they do not care what the service does or what it's called, they just want a problem solved and to be confident that the service is capable of resolving an issue they are facing.

(Older participant, Rhondda Cynon Taff)

However, many older people also involved in the fieldwork were at least as concerned about process:

Concentrating on outcomes strikes me as simplistic. There is something about the value we place in relationships and someone making a commitment to you.

(Older participant, Warwick)

If older people know that you are independent then they know that you are acting for them. Even if they are not happy with the final outcome, at least they know that you have tried. You've been in it together.

(Older participant, Rhondda Cynon Taff)

This premium on process has been found among a range of services and users of services (Harding and Beresford, 1996; Williams, 1998; Qureshi and Henwood, 2000). In the development of standards for information, advice and advocacy services for older people in particular, the impact of such processes can be captured in terms of 'service process outcomes' (Qureshi *et al.*, 1998). Thus, tensions between process and outcome can be relieved by recourse to both.

### ***Costs and benefits***

Resources of time and money can be stretched in meeting and maintaining quality frameworks and associated commitments.

For small community organisations providing information, advice and advocacy services these resources can be particularly scarce and the costs can have a significant impact:

It is hard to meet all the standards ... the CLS, FIAC [*Federation of Independent Advice Centres*], the funders and the rest. It can cost a lot to register and then meet all standards, regulations and so on.

(Black older people's community worker, Manchester)

However, such costs are more easily and readily borne by the services if the required standards are themselves meaningful and the benefits outlined above are clearly manifest. Otherwise:

There is a risk of serving the standards not the people ... becoming driven by numbers, ticking boxes and easily measurable outcomes.

(Community worker with older people, London Borough of Camden)

### ***Whose standards?***

Having highlighted the desirability and explored some of the challenges and opportunities for the development of standards, a further question raised within the advocacy movement in particular is that of the origins and ownership of such standards (Older People's Advocacy Alliance, 2002). Concerns are largely centred around standards

- being created and imposed from above or outside, by government or other agencies

- not matching each of the different forms of information, advice and advocacy services for which they are intended
- fulfilling the organisational imperatives of policy makers, commissioners and other providers, rather than those of the information, advice and advocacy services and their users.

At the end of it there is always a bureaucrat. We have to please them, but we must be true to ourselves and our customers.

(Older participant, Warwick)

It is crucial that those involved in the management and running of information, advice and advocacy services are themselves engaged in the development of standards. There is evidence of a growing willingness to take the initiative and the responsibility for developing appropriate standards, galvanised by government interest and grass-roots demands, within advocacy as well as more established information and advice services (Henderson and Pochin, 2001; Barnes *et al.*, 2002; Older People's Advocacy Alliance, 2002):

There has been a big shift from the mindset of 'standards will destroy us'. Current efforts to resolve these matters ourselves need to be respected and supported by Government ... from a democratic perspective, which resists the reduction of information, advice and advocacy services to a mere adjunct of service delivery.

(Management committee member, national older people's advocacy organisation)

Moreover, it is essential that older people are engaged in work on the creation, implementation and monitoring of standards for information, advice and advocacy services intended for older people. The benefits of doing so have already been outlined elsewhere in previous chapters of this report, and should be no less significant than has been demonstrated to be the case for other groups, settings and services (Shaping Our Lives, 1997; Raynes, 1998; Audit Commission, 2004a, 2004b):

We need to privilege users' experience within standards and evaluation of quality, without jettisoning more organisationally focused measures of process and outcomes that are central to effectiveness and accountability.

(Management committee member, national older people's advocacy organisation)

### **OPAAL**

The Older People's Advocacy Alliance (OPAAL) UK is an alliance of advocacy schemes and national and local organisations of older people and for older people. OPAAL was formally constituted in 1999. Its aims are the promotion and development of independent advocacy services with older people; and the establishment of standards and quality frameworks for the delivery of such advocacy. Feedback from member organisations, research and other activities carried out by OPAAL showed consistently that there was a lack of recognition and resources for independent advocacy with older people as well as a need to address availability, capacity and quality standards.

*continued overleaf*

OPAAL has received Section 64 funding from the Department of Health to undertake a ground-breaking national project in England that focuses on the following themes:

- guidance on good practice
- the evidence basis for advocacy
- standards and quality frameworks
- involving older people in the promotion of independent advocacy
- the case for independent advocacy for older people as a right
- acknowledging diversity and difference.

The project is innovative in bringing together advocacy practitioners with older people (whether as advocates, users of advocacy services or representatives of interested organisations) to work together on the above themes to achieve change and development.



## **8 SUGGESTED PRIORITIES FOR FURTHER WORK**

Having explored the meanings of information, advice and advocacy; considered older people's perceptions and views on 'good' services; and analysed some of the key developments in these fields, the following interrelated priorities are proposed in terms of research, policy and practice.

### **Research**

- A comprehensive, consistent and compelling account of the need for information, advice and advocacy services, and the needs of older people regarding these services has been plotted by numerous pieces of research over the two decades drawn on for this review. The call from older people is to now move on to research that helps make it happen – overcoming the barriers, identifying what works, sharing good practice and engaging older people themselves in the process.
- Advocacy with older people remains a relatively under-researched area. There is a need for further work on conceptualising, mapping and modelling as well as measuring the effectiveness of advocacy with older people. Given the dynamism and pace of development in the field at present, there will be a need for ongoing analysis of

emerging policy and provision in information, advice and advocacy for older people.

- There is a need to examine relative meanings and relationships between information, advice and advocacy and other forms of support, including service brokerage, mediation, counselling and befriending. Such services can also empower and enable older people to take control and enhance the quality of their own lives. They have similarly been late to develop and less readily available to older people than to other groups.
- Furthermore, there is a need to explore and further develop more sophisticated linkages and relationships between information, advice and advocacy services than suggested by a crude continuum. The idea of circles of support could help to advance more accessible and appropriate patterns of provision that start from where the older person is rather than from an assumed point of entry.
- More research is also required to build an evidence base towards the further development of quality frameworks, standards and evaluation tools, particularly in relation to advocacy as currently being promoted and developed by OPAAL. Again, the engagement of older people in such research helps to ensure that it is more robust, relevant and rounded.

## **Policy**

- Information, advice and advocacy for older people need to be placed high on the policy agenda, as a priority issue in the development of strategies and services for an ageing

population. They can be essential to preparation, participation, prevention, protection and power throughout the life course. As such, they are indeed keys to continuing independence and remaining in control of one's later life.

- There is a strong case for a legal right to independent advocacy and legal status conferred on the advocate. This would help to ensure recognised and more readily accessible services as well as to secure the citizenship rights of older people in need of such support. Requirements placed on statutory authorities to make provision for information and related services should be extended and strengthened in order to include support for independent advocacy, as is already the case in Scotland.
- Government, statutory and voluntary organisations should move from consultation to the engagement of older people in the development of information, advice and advocacy services at a policy level. This shift has begun to happen on the back of initiatives such as Better Government for Older People, the Strategy for Older People in Wales and progression within the older people's movement. With regard to policy development for information, advice and advocacy services, the engagement of older people would help to secure the kind of principled and effective services envisaged by the participants who contributed to this report.
- National minimum standards should be developed for independent advocacy with older people. Such standards should take account of principles and effectiveness as well as processes and outcomes of advocacy. Government

should support the development of such standards by and with advocacy organisations and older people. While recognising the potential limitations and tensions, the advocacy movement should also give active consideration towards working with the Community Legal Service on the development of a distinctive quality mark for advocacy services where appropriate.

- A more strategic and 'joined-up' approach is required towards policy development within government departments and devolved administrations; between Government and the grass roots; and across statutory and voluntary organisations at a local level, in order to meet the information, advice and advocacy needs of older people. The advent of the Link-Age initiative provides a significant opportunity to demonstrate such an approach in practice and to elevate the status, scale and scope of information, advice and advocacy services for older people.

## **Practice**

- Providers of information, advice and advocacy at local level should clearly define their own services. This should take account of the specific forms of information, advice and advocacy being practised, along with the focus of the work in terms of particular social groups, situations and settings. Here it is important not to over-promise and under-deliver or to purport to be a panacea for all ills. Such clarity is crucial in showing policy makers, commissioners, providers and older people what is readily available and where gaps exist.

- Statutory and voluntary organisations that provide information, advice and advocacy services as well as direct services should seek to support and enable the development of independent information, advice and advocacy. This requires a clear understanding of the meaning and necessity of independence according to the particular form and focus of the information, advice and advocacy being provided. It also calls for a highly principled approach in which the interests of older people are elevated above the business interests of those providing direct services.
- A diversity of older people should be engaged in the work of information, advice and advocacy services intended for older people. This involvement may take place at all levels of the management and running of the service, acting as management committee members, developing standards and quality frameworks, building alliances, monitoring and evaluation, as well as providing information, advice and advocacy on a peer basis.
- Local information, advice and advocacy services should seek to make a positive contribution to the national debate, development and delivery of standards and quality frameworks. This would help to ensure effectiveness and safeguard key principles of these services at an organisational level, and within the work of staff and volunteers at an individual level. Taking responsibility for such development may also help to ensure that standards and quality frameworks are not imposed externally or from the top down.

- Information, advice and advocacy services should adopt a strategic approach towards 'joining up' with other agencies and allies. Such an approach includes making links with relevant initiatives in policy and provision by government, statutory and voluntary organisations in the interests of older people. It also involves making alliances and networking with other advocacy schemes, groups and social movements dedicated to human rights for all ages:

Information, advice and advocacy are distinctive services, but they are like spokes on a wheel. We need one and all of them to work well to keep us up and running ... moving in the right direction.

(Older participant, Warwick)

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