

# **Older people's perspectives**

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# **Older people's perspectives**

**Devising information, advice and advocacy services**

**Ann Quinn, Angela Snowling and Pam Denicolo**

The **Joseph Rowntree Foundation** has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of the Foundation.

Joseph Rowntree Foundation  
The Homestead  
40 Water End  
York YO30 6WP  
Website: [www.jrf.org.uk](http://www.jrf.org.uk)

© University of Reading, Department of Health and Social Care 2003

First published 2003 by the Joseph Rowntree Foundation

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A CIP catalogue record for this report is available from the British Library.

ISBN 1 85935 107 7 (paperback)  
ISBN 1 85935 108 5 (pdf: available at [www.jrf.org.uk](http://www.jrf.org.uk))

Cover design by Adkins Design

Prepared and printed by:  
York Publishing Services Ltd  
64 Hallfield Road  
Layerthorpe  
York YO31 7ZQ  
Tel: 01904 430033; Fax: 01904 430868; Website: [www.yps-publishing.co.uk](http://www.yps-publishing.co.uk)

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# Executive summary and recommendations

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This study explored the needs and problems of the diverse communities of older people in Slough in relation to information, advice and advocacy. A research team from the University of Reading interviewed older people, both individually and within focus groups, as well as service providers. Recommendations for services that would meet the needs expressed by older people were developed, and solutions were then prioritised by older people and representatives of organisations of and for older people in Slough. The study found that:

- Older people experienced barriers in accessing information, advice and advocacy in three stages:
  - 1 becoming aware that there was information, advice or advocacy that could help in their situation
  - 2 gaining access to appropriate and comprehensive information and advice
  - 3 receiving practical assistance to act on the information and achieve a solution.
- Distinctions between information, advice and advocacy were not generally helpful to older people. Older people welcomed advice that helped relate information to their particular circumstances, and assistance to obtain the services they needed.
- The large volume of information available could be as problematic as the absence of information.
- Older people valued information that was topic based, rather than the agency-based information that was more frequently offered.
- Areas of concern for older people could be overlooked by service providers, if they did not fit within agency guidelines for service provision.
- Older people had diverse approaches to obtaining information. Different modes and styles of information suited people at different times, and in relation to different topics. They

wanted timely information, often at a point of change or crisis in their lives, and they wanted comprehensive information actively offered in their first language at such stages.

- Older people desired continuity of contact, to avoid having to retell their story to new people. A follow-up service was also appreciated, ensuring a solution was achieved, rather than simply being referred on to yet another potential source of information.
- Older people were as interested in information and advice about leisure activities, and how to access them, as service provision for illness and infirmity.
- Services struggled to provide accurate and comprehensive information to older people, in the absence of resources to develop and maintain co-ordinated information databases.
- The preferred solutions most frequently chosen by older people and organisations of and for older people were:
  - 1 an information bank, to provide a comprehensive and updated source of information for the information providers, also accessible to older people
  - 2 an information centre, to provide a point of contact for older people.

## Recommendations

From this project in Slough, it seems that there is no single solution that can meet all the needs expressed by the diversity of older people.

Services in the statutory sector have recognised the importance of information provision, and are planning a number of initiatives. It is recommended that:

- Instead of separately providing information around relatively narrow service definitions, statutory sector services work with voluntary

## Older people's perspectives

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organisations to set up a comprehensive and co-ordinated database.

- The database includes information about quality of life matters, such as leisure activities.
- Resources are set aside to update and maintain the database regularly. Slough library could be considered as the host organisation.

- The database is accessible to a range of agencies, distributed as widely as possible so as to be accessible to older people in their communities.
- Instead of setting up their own separate information resource centres, statutory sector services work in partnership with voluntary organisations to provide a more comprehensive information centre for older people.

# 1 Background to the study

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## Introduction

The need for improved information and advice services has been acknowledged in government policy documents, alongside an increasing emphasis on the importance of service providers working in partnership with older people. However, there is little exploration into the models of information provision used, and a lack of clarity about what is encompassed by information services.

There are few examples of information and advice services controlled by older people. Current government policy aims to involve older people as partners, rather than simply as recipients of service (Cabinet Office, 1998). In considering involvement and partnership, however, information-giving and consultation are often presented as participation. Assumptions about the involvement and participation of older people are diverse and frequently implicit rather than explicit (Carter and Beresford, 2000).

## Local context

Although an area of high deprivation, Slough is also a diverse, multi-ethnic community, with over a third of the population belonging to minority ethnic groups (2001 census data). The various South Asian communities – people of Indian, Pakistani and Bangladeshi origin – are the largest minority ethnic group, comprising over a quarter of the total population. While over 13 per cent of the population are older people of pensionable age, the South Asian communities tend to be younger. In the 1991 census, just under 7 per cent of people from the minority ethnic communities were of pensionable age; the figures from the 2001 census are awaited.

Slough Borough Council, together with local health trusts, has consulted with a range of organisations both of and for older people, opening up the opportunity for group advocacy by older people. Structures to facilitate this include:

- The Slough Older People's User Group, which consists of older people who are users (or potential users) of services in Slough.
- The Slough Older People's Forum, which includes members of organisations (both voluntary and statutory) offering a service to older people meeting alongside members of the User Group.
- The Partnership Board. The Partnership Board (until recently, known as the Older People's Strategy Group) is chaired by a member of Slough Borough Council's Social Services department; it also includes representatives of housing and transport departments, the various health trusts, the Older People's User Group, and community organisations. The Partnership Board informs council and health sector planning.

The Slough Older Person's Forum wished to establish a 'one-stop shop' to provide information and advice about a broad range of services of interest to older people, and to act as a base for a number of the voluntary organisations offering support to older people. It was not clear as to what might be the most appropriate model for such a service, nor who would be involved in it, where it might be sited, and who would fund it.

There was a range of information, advice and advocacy services in Slough available to older people, although not necessarily specifically focused on their needs. Slough Borough Council had recently set up their own one-stop shop, to give information about all council services. The Council for Voluntary Services had an information service, there was a Citizens Advice Bureau, and Age Concern had a range of information and advocacy services they wished to extend further. Developments in both information and advocacy were planned within the health sector.

### The research bid

There was interest amongst older people's organisations in developing additional information, advice and advocacy services. Although organisations had individually made considerable efforts to develop services, there was little co-ordination and evaluation of these services from the users' perspectives. The value to potential users of the information advice and advocacy projects, both proposed and existing, was unclear, and possible overlaps between the services needed to be examined.

Market research – research that would help make the case for the services they wanted – was seen as potentially useful. A research group was formed consisting of a three person team from the University of Reading in partnership with representatives of seven organisations based in Slough, including those run by older people and those for older people (see Appendix 1 for the list of partners). This research group was known as the Project Working Group (PWG).

### Aim of the research

The overarching aim of the research was to draw on the experience and expertise of older people, and of the relevant voluntary and statutory agencies, to discover what older people value in

terms of information, advice and advocacy services, and appropriate models for the delivery of such services.

This would be the first stage of a project to develop co-ordinated provision of information, advice and advocacy services for all potential older users within Slough. It would provide Slough Older People's Forum with the knowledge necessary to recommend any new information, advice and advocacy services, and gather the evidence necessary to influence decision-making.

### Approach to the research

In order to do this effectively, the research group aimed to work with the Slough Older People's Forum and service providers to clarify:

- what information provision is currently available, and how this is viewed both by users and those older people not availing themselves of it
- how an extended and co-ordinated provision could be worked towards
- the most appropriate means of providing such information services from the users' perspectives.

See Chapter 14 'Methods' for further details.

## 2 The need for information, advice and advocacy services

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

*It's like going into a restaurant without a menu. How do I know what I want if I don't know what is available? (Older person)*

### The older people's perspective

We interviewed 13 older people in depth, and had group interviews with over 100 older people in different community settings across Slough (see Chapter 14 'Methods').

Older people wanted information across the range of health and social care services, particularly following the onset of illness (either their own illness or that of a family member or friend). The need for information and advice about welfare benefits was frequently mentioned, as was assistance in filling in complex benefit claim forms.

*Mostly all the forms are difficult to fill up, mostly I get help because you get the wrong idea and don't get all the allowances you should. (Older person)*

Older people lacked information about reliable trades people who could do household repairs, and also gardening and lawn-mowing.

*There is a risk of getting a cowboy. What would have helped is a sort of list of official guidance about which firms you can trust. The other thing is a gardener. Nobody wants to know when you ring about gardeners. (Older person)*

### Information, advice or advocacy?

Service providers distinguished between the provision of information, advice or advocacy. For older people, this distinction appeared less useful. They wanted assistance or help in order to receive a service, and did not distinguish between information, advice or advocacy as services in their own right. Information was seen as a means to an end, not an end in itself.

Receiving too much information could thus be as problematic as too little.

*It was confusing because there were too many choices in the end. Advice from Arthritis Care was from a free phone number. The NHS free phone number I used also, and talked to a number of other societies. But then I found I was getting an avalanche of literature. You wonder if it is the right advice, and who you are talking to. (Older person)*

Information that did not lead to a service, or a solution to a problem, was not valued.

*I wanted to go swimming. I found out from the leisure centre when their over 50s sessions were, but it was no use. There was no transport I could use to get to the pool, so it was no good. (Older person)*

The concept of advocacy was rarely recognised amongst older service users. This was particularly so for older members of the South Asian communities in Slough: the term 'advocacy' has no exact equivalent in Asian languages, and the interpreters for this study used words meaning 'help, support or assistance'.

### 3 Accessing information, advice and advocacy services

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#### Different approaches to access

Older people had diverse approaches to obtaining information, advice and advocacy. Some were self-sufficient seekers of information; others were more reliant on other people.

*Older people attending a social club in Slough were asked where they obtained information. They pointed towards two of the members, laughing. One was an organiser for the group, and she obtained much of her information through her links with Age Concern; the other independently accumulated information from a wide range of sources, including local papers and the library. (Research field notes)*

Self-sufficiency could develop through necessity.

*When I became ill and was stuck at home people gradually disappeared or didn't contact me any more. Then you have got to find your own outlets from the news, the media, who to contact. (Older person)*

Older people who were not self-seekers did not usually turn to formal information and advice services, but asked the people who were already helping them, family and friends as well as professionals. However, health and social care staff were not always aware of the full range of services, only those offered within their own system.

*My wife had a slight stroke and it affected her waterworks and I had to change the bedding twice one night. I mentioned it to my doctor, and she referred me to the continence nurse, but while she was very helpful sending me lots of samples [of incontinence pads] she didn't say that I could have them free from the district nurse. So I was paying £2 a day for these, until I read a leaflet from Help The Aged at the hospital. Now I hear Slough Council have a laundry service for soiled linen – why don't they tell you about all this? (Older person)*

#### Major barriers to access

Lack of awareness of potential help for their situation was a major barrier for people taking the first steps in seeking information, advice or advocacy. If they did seek information, a further barrier occurred when staff provided only partial information, perhaps describing the services available from their own organisation rather than giving a more comprehensive picture of the services that could meet the older person's needs. Knowing where to start, and what questions to ask, could be problematic.

*I asked the council for an assessment but they asked 'what type?' and I didn't know what to ask for. (Older person)*

Finally, barriers could prevent people acting on the information they had received. Lack of appropriate transport was often cited as preventing older people accessing a desired service. Organisation guidelines could also place barriers in the way of older people.

*We are not allowed to fill in forms for people, or write letters for them. They bring me in a letter and form, and I can translate what it's saying, but I can't reply for them. They have to go somewhere else for that: I refer them to voluntary organisations or the CAB, or to welfare rights officers. (Service provider, public sector)*

While this study was aimed at exploring information, advice and advocacy, older people frequently referred to difficulties with transport. Knowledge about a service was rendered pointless if that service could not be accessed owing to unavailability of appropriate means of transport, or if staff shortages meant that the service was not currently available.

## 4 Preferred style of service

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### Focus on topics, not agencies

The older people interviewed valued information that was presented in relation to concerns of importance to them (needs-based information) rather than information presented in relation to provision from a particular agency (service-based information).

*When I rang this lady about the welfare form and mentioned gardeners she said 'No, I'm assessing what needs your wife has'. She said 'Gardening isn't on the list' but I said 'By golly, it has to be done'. She said 'Gardening doesn't help your wife', and I said 'It does'. She said there is a firm line, and gardening is not to do with attendance allowance. (Older person)*

The staff member quoted here may have been strictly accurate in that the need for gardening assistance would not be considered grounds for obtaining attendance allowance. But she was also dismissing an issue that very much concerned this man who was acting as a carer for his wife; gardening absorbed time he wanted to spend caring for his wife, and it caused him distress if his garden was not looked after. Other examples reinforced a picture suggesting that service-led rather than needs-led assessments of older people were common in the public sector, with areas of concern for individual older people being ignored if they did not fit within agency guidelines for service provision. Older people tended to see their needs in broader quality of life terms rather than the more narrow service agenda of health and social care providers.

### Accuracy of information provided

Accuracy of information was obviously important. However, there were topic areas such as welfare benefits for people with dementia, where older people frequently received inaccurate information.

*I rang and asked about attendance allowance and was told it was a mental case so she wouldn't be entitled to any benefit – well, they said it was only for physical problems. (Older person)*

He eventually discovered that his wife's needs would entitle her to attendance allowance, but during the delay valuable income had been lost (benefits are rarely backdated, and if so, usually only for a three-month period).

Older people's expectations of accurate and comprehensive information may seem modest, but this study demonstrated just how difficult this was to achieve.

Despite the efforts of staff, services struggled to provide accurate and comprehensive information in the absence of co-ordinated and regularly updated information databases. The difficulty in obtaining information across agencies regarding availability for particular situations was frequently evident. Current directories of services tended to be agency based rather than issue or topic based.

### Perceived trustworthiness of information provided

The perceived trustworthiness of the information provider was also important. In some topic areas, the independence of the advice giver was valued; in others, it was the advice giver's expertise. Independence appeared particularly important in relation to financial and benefits advice.

Expertise was valued, as it enabled the mass of information available to be tailored to the needs of the individual older person, emphasising what was relevant and necessary in their particular circumstances. Older members of the South Asian communities in particular saw the need for a preliminary meeting, to assess whether the person was trustworthy and had the necessary status to respond effectively to the problem.

### Personal assistance versus paper-based information

Many older people valued personal assistance, especially those whose ability to seek out information for themselves was restricted by disability or the demands of caring. Continuity of contact and follow-up helped to instil trust, and confidence that the problem would be resolved.

*The personal touch: it is exhausting and resource heavy but makes such a difference.*

(Service provider, PWG member)

This comment reflects the widespread view that it was 'people rather than paper' that mattered in providing information.

*It was such a relief when she [social worker] came, after all those leaflets.* (Older person)

Paper-based information clearly has a place, especially in the more straightforward, non-emotive topic areas. The above quotation is from an older person with cancer, whose finances and physical and emotional energy were all diminished following an intensive course of treatment. Personal assistance made all the difference: in his words 'It turned my life around'.

Paper-based information was of limited use for older people from minority ethnic communities. Translating written information into the main languages spoken by the various minority ethnic communities was not always helpful. Those older people from South Asian communities who did not speak English were disproportionately likely to be unable to read their first language. However, such information could be read and conveyed to them by other community members.

### Comprehensive, co-ordinated and timely information

Older people valued the active approach taken by the health and social care staff who advised them of additional services they could receive.

*My mother had various accidents when district nurses were required, and the funny thing is, I started to get advice off the district nurse. She started to say 'oh, you ought to do this' or 'your mother needs that' and got social services to send somebody to help her get dressed every morning and go to the day centre every week because it was good for her mobility and meeting people.* (Older person)

Older people wanted timely information at key points in their lives, often a time of crisis or change. They would welcome comprehensive and co-ordinated information actively offered at these points. There was a feeling that they were receiving too little information, too late.

*I would feel a lot happier if somebody had given me a sheet of paper with all the contacts, what you get free and what welfare benefits you could get, right at the outset [that is, at the time of diagnosis of an illness].*

*There could be a system where an administrator at the health centre has a list for who you go to for what.* (Older person)

## 5 Diverse solutions

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Unsurprisingly, there was no one service solution suggested that could meet all the needs for information of all the older people in Slough.

### **Generic community services or services specialised for older people**

A particular division was found between those who would welcome a more generic or mainstream service, and those who would prefer more specialised services, whether these specialist services were for older people or for different minority ethnic communities.

There were diverse views as to whether older people should receive information and advice from services designated as specialist services for older people, or whether they should use mainstream information and advice services. Some older people did not perceive themselves as old, and would not readily access services labelled for older people; some did not like the concept of being solely with other older people. Others welcomed the high profile of a service such as Age Concern, as providing a contact point where they knew they were likely to be helped.

### **Multi-cultural or differentiated, culture-specific services**

Similar diversity surrounded views about the need for specialist services for the various South Asian communities. Some argued for multi-cultural services, responding in culturally appropriate ways to the needs of all. Others argued the case for specialist services for each community. Amongst the latter, there were some who saw it as a transitional need: older people had lived through partition, and thus the different communities would not readily mix together, but younger

people without this history would feel differently. Others had a contradictory view: the older people were comfortable about mixing together, but the younger generation were more radical, desiring separate services and insisting on this for their older relatives. In practice, some services succeeded in bringing together older people from across the South Asian communities, but others appeared dominated by a particular group, which in turn discouraged attendance by the other groups.

### **Translation issues**

A number of the older people from South Asian communities did not speak English. The numbers of staff fluent in appropriate languages were few and scattered thinly across a range of agencies. Interpreters were frequently used, and their role boundaries were blurred: they often provided information, advice and advocacy alongside translation. One person might work, in slightly different capacities, for a number of different voluntary agencies, increasing the blurring of roles. If staff or volunteers were members of the same community as the older person, it meant they could help provide a culturally appropriate service, not just a translation. But membership of the same community, and multiple roles and links within that community, meant that some older people were concerned that confidentiality could be breached.

*In the Asian culture, we and our children have to abide by the family cultures. They will help them and then they will find out. This is the major solution in the Indian culture. In our community we exchange and share information. (Interpreter)*

*Indian people sometimes like privacy themselves. (Older person (Indian))*

## 6 The perceptions of service providers

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We interviewed 23 key informants, from services providing a range of different information, advice and/or advocacy services to older people.

### Who are 'older people'?

Definitions of 'older people' – at what age they were or were not eligible for a service – varied considerably. For example, Age Concern set eligibility for some services (such as the advocacy service) at age 50 and over, for others (such as the Handy Person service) it was age 60 and over. For the advocacy project People in Partnership, age limits operated in the other direction: the age limit for their advocacy service for people with mental health problems was 70 or under. These age variations appeared to reflect the priorities of statutory bodies when funding a service, but such variations make it difficult for older people to be sure of what they are entitled to.

### Reliance on key individuals

Many of the agencies relied on a few key individuals who were outreach workers and specialist providers of benefits advice or advocacy services. These were people able to work across agency and project boundaries. Amongst the South Asian communities not all individuals who worked in this way were equally valued: they needed to be seen to have status and the power to effect change and a manager's title was valued. Many informants noted the relationship between information and power.

The reliance on just a few key people created problems when they left (either voluntarily or because funding ceased) and an important source of information was lost.

The loss of a member of staff with language skills, and who was viewed as 'culturally competent' could have a considerable impact within the South Asian communities:

*She used to be my main link and because she had the languages and would go out and do assessments it was a great help. ... I haven't been in touch [with the Agency] for a long time now, because I don't know who came into that position and nobody introduced themselves.*

(Service provider, voluntary sector)

### The range of potential information

The range of information that potentially needed to be available covered a broad spectrum: topics from dementia to household repairs, adult education to dance clubs. No one agency could provide specialist information about all possible topics. The service representatives interviewed differed as to whether the information, advice and/or advocacy they offered was of a general nature, or tailored to specific needs, or fell somewhere in between – some service providers offering a more or less specialised service, referring on to other providers when the information needed moved out of their sphere of expertise.

### Definitions of information, advice and advocacy

Services differed as to whether they offered all three of information, advice and advocacy, or whether only one or two of these were offered. The boundaries between all three activities were fluid, with different services, and probably different staff within any one service, holding different views as to their nature.

Definitions of advocacy in particular varied, and some of the more specialist advocacy providers did not recognise the advocacy offered within other services as 'true' advocacy, reflecting the more widespread debate about the nature of advocacy. There were strong views about whether or not employees of a service could act as an advocate for service users with respect to that service. Equally

strong views were held by those who argued that the only true advocacy was 'self-advocacy': the service user being enabled to act as their own advocate. However, the majority of staff interviewed saw advocacy as an appropriate part of their role. Interestingly, it was advice that was more frequently described as problematic in practice.

Staff frequently distinguished between giving information and advice: advising was seen as a more skilled role compared with information provision. In some cases, there was a reluctance to offer advice, because it was thought that they lacked the necessary expertise or training. It was also feared that there might be some legal comeback if the wrong advice was given. Similarly, some agencies had guidelines that prevented their staff from completing forms or writing letters for older people. This seemed to reflect a mixture of concern about resources (staff time) and legal responsibility if something went wrong.

*Well, I see advocacy as helping people understand what are their rights, and that to me is a legal matter. We decided right at the beginning there was a distinction between information and advice, and we were on information. We would provide people with contact names, phone numbers, we'd be signposting them and then they would have an option of using that information or not. (Service provider)*

### Diverse models of provision

Some agencies had what they described as an empowerment model, which meant that they would normally provide older people with a contact as to where they could find the necessary information for themselves; they saw this as encouraging and maintaining the independence of older people. It was emphasised that not all older people needed personal assistance in obtaining information or advice: some simply needed to be pointed to where information could be obtained,

and advised to get back in touch if this was not successful.

However, some older people had a particular need for information at a point of crisis in their lives: agencies recognised the need of such people for more of 'a personal touch'. For service providers, the skill lay in recognising when it was appropriate to offer a signposting service, and when, for whatever reason, it was more appropriate to act on the older person's behalf in finding the relevant information. There was also skill (and knowledge) required in order to offer the accurate contact details.

*I was phoned by someone at the end of her tether, she hadn't been able to find out the information she needed about obtaining a service. She was too distressed to simply pass on to someone else, so I said I would find out the details and get back to her. It took me 12 phone calls, and I thought I knew the system in Slough really well. I would phone someone, they would pass me on to someone else – sent around the houses! (PWG member)*

Services operated with different models of information provision, ranging from providing information about services that exist, to assisting older people to obtain the help they needed. Some saw information-giving as a matter of 'signposting', anything else moving into an inappropriate sphere of advice or advocacy.

*I see us very much as almost like a mobile signpost. People come to us and they may say 'Oh I need, you know, I have a mother with Alzheimers, can you put me in touch with an Alzheimers group?' and we'll look it up and say 'Oh yes, Mrs Smith, there's the phone number.' ... We often refer to Age Concern, Crossroads, the bus companies for more information. A fair few queries are about benefits in which case we normally supply the government leaflet and then supply the phone number of the local Benefits Agency. (Service provider (Information service))*

## Older people's perspectives

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Other service providers had a wider view of information provision, perhaps because information was only part of their role, and saw a greater need to help people determine what it was that they wanted. A member of staff who is fluent in a number of the languages spoken within the South Asian communities commented:

*Looking at them, I know the majority of the time what community they represent. I don't speak any English, I go straight into their language so any barriers are dropped at stage one. They will tell me exactly what it is. Sorry, I take that back. They wouldn't be able to tell me exactly what it is, they'll*

*just tell me the full story. It's never happened that they could pinpoint what their problems are. They would just tell me the whole story which I have to sift by the end of the conversation. They are looking after a disabled person in the family and they're losing out on benefits or there's a problem. They cannot go to their religious places. They're under a lot of pressure. So they give me all the information that they have and will just open up and it's my job by the end of the day to sit down and think, OK, this is the bit. Then I explain to them, this is the bit I can take care of. These are the bits I'll pass on to the relevant agencies which can help you.*

(Service provider, voluntary sector)

## 7 The impact of resource limitations

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Service providers were struggling to offer timely, accurate and comprehensive information. Updating their own information base was difficult for the majority of services; few had the administrative resources to facilitate this. Agencies tended to prioritise service provision, rather than developing and maintaining information databases. In many cases, information resulted from the networking skills of individual staff members, and was kept within those individuals' diaries – or heads.

There was concern about the potential duplication of effort within hard-pressed agencies, all attempting to update their directories of services and information, as well as the possibility of gaps in knowledge: 'It's a bit hit and miss' (PWG member).

### Short-term funding and re-organisation

The current context of service delivery in Slough compounded the difficulties. Services in both the public and the voluntary sectors were under considerable pressure. For the voluntary sector, the short-term nature of their funding meant staff time was continually diverted from service delivery to fund raising. It was easier to get funding for new projects than to continue existing projects. There was considerable frustration at the need to constantly change and repackage their services in order to obtain funding: 'We're continually running pilots' (PWG member).

As a consequence, there was a rapid turnover of projects, making it difficult to keep track of what was available.

Almost all the voluntary agencies were dependent on funding, which either ceased at the end of the financial year or was subject to review. Interviews with service providers revealed widespread concern that further funding would not be forthcoming or that it would be reduced. Staff who were busy searching for alternative sources of funding were effectively removed from the service thereby reducing what could be offered.

The public sector had faced almost continual re-organisation over the past years, with physical moves of offices alongside structural and role changes. It was hard to keep track of who was responsible for what, where they might be based and how they might be contacted.

*What happens is when people move the new person that comes in, there is no way or no set procedures in how they can introduce themselves to the agencies. It's only when you go out to meetings and they're representing the organisation and they're there that you find out. Otherwise, word of mouth.*

(Service provider, voluntary sector)

During the 12-month period of this study, 5 of the 23 services where we had interviewed key informants came to an end, either because funding ceased, or following re-organisation.

A further problem with the continual change in the public sector resulted from the way committees and services were renamed and repackaged, sometimes with little substantive alteration, making it difficult to keep up with the current situation. The ever-changing guidelines for welfare benefits was a frequently cited example.

### The impact of staff shortages

There was a shortage of staff in the public sector, restricting the services available to older people, and a high turnover of staff. At the time of our study, there was a considerable shortage of district nurses, and of occupational therapists and social workers in the council team responsible for delivering services to older people. The restrictions on public spending meant posts tended to be frozen, and thresholds of need for receiving a service increased.

It also meant that staff had less time and energy to spend on networking and information gathering.

*There are issues about information generally and how it is provided and communicated by service providers.*

## Older people's perspectives

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*You ask someone at a GP's office if they know about something to do with the voluntary sector, and they don't. They say 'We haven't got the time'. They don't mean it in a pejorative sense – they literally don't have time. And yet they are the obvious point of contact for so many people.*

(Service provider, voluntary sector)

## 8 The Project Working Group

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### The nature of the PWG

One member of the University of Reading research team (Angela Snowling) had met older people's groups while working in Slough as a health promotion officer. Knowing of their interest in information and advice services, she initially brought together seven representatives from organisations based in Slough to consider whether to participate in this Joseph Rowntree Foundation study. Although they agreed to bid for this research money and ultimately form a PWG, members of the voluntary organisations in particular had reservations. They wanted to establish a 'one-stop shop' in a central Slough area, to provide advice and information about a broad range of services of interest to older people, to act as a base for a number of voluntary organisations offering support to older people, and to offer a positive image of old age.

Essentially, they knew what they wanted: a service, not research. For organisations operating on very restricted budgets, it was hard to see a comparatively large sum of money allocated to research rather than to much needed services.

### Fulfilling needs

The research project became more acceptable once it could be perceived as market research. While there was consensus about the desirability of a 'one-stop shop' there was less clarity about the most appropriate model for such a service, where it could best be sited, and how it might link with existing services.

Although organisations in Slough have individually made considerable efforts to develop successful information, advice and advocacy services, co-ordination and evaluation of these services from the users' perspectives was undeveloped. Mechanisms were not identified

whereby the information flow could be two-way, so that older people would not only be recipients of information about current provision, but also be helped to identify and argue for the range of provision they want. PWG members identified the research as an opportunity to build a case to obtain funding to develop their information, advice and advocacy services.

### Working together

The University research team had anticipated the PWG would develop as a 'learning organisation'. The notion of learning organisations, with users, carers and providers open to learning from each other, is identified by Barnes (1997) as essential for the development of active participation. User groups require their own infrastructure for learning, to have the knowledge with which to argue a case with service providers (O'Keefe and Hogg, 1999).

However, this did not develop as planned. Attendance at the PWG meetings fluctuated considerably. Apart from the University research team, none of the other members attended all of the meetings. When a representative did attend the meeting, they sometimes brought several other members of their organisation with them. Understandably, they were less interested in the process of the research, than they were in the findings and how the research project might be used to obtain funding for information, advice and advocacy services.

PWG members were also members of the Slough Older People's Forum, and it was agreed to join the Slough Older People's Forum for the last meeting of the PWG, to involve a larger group of older people in prioritising the service solutions suggested from the research.

## 9 Needs and solutions

The needs emphasised within this study, and the solutions suggested to meet these, are summarised below. A brief description of each solution is then given. The solutions were suggested by a number of sources: from literature and reports of successful services elsewhere in the UK as well as from the research interviews in Slough.

An initial exploration of successful schemes developed elsewhere was undertaken prior to the research interviews with older people, so that a range of solutions could be considered during the interview: there was a concern that otherwise older people's views might be based on low expectations of what could be possible.

### Summary of needs and solutions

Need: Accurate, comprehensive and co-ordinated information for the information providers

Solution 1: Information bank

Solution 2: Training for staff

Need: Comprehensive and co-ordinated topic-based information

Solution 1: Information bank

Solution 2: Training for staff

Solution 3: Work group of older people

Solution 4: Information centre for older people

Need: The human touch (people rather than paper): a trustworthy source of information, offering expertise and independence

Solution 4: Information centre for older people

Solution 5: Trained reception staff

Need: Timely information, available at points of change or crisis in life

Solution 2: Training for staff

Solution 6: Information packs for older people

Solution 7: Information packs about particular illnesses

*(Continued)*

Need: Culturally appropriate services

Solution 8: Collaboration between organisations for older people and services supporting people from particular cultural groups

Need: Reliable people to do household and gardening tasks

Solution 9: A social business register

Solution 10: Barter scheme

Need: Involvement of older people in decision-making, to identify and plan the services they want

Solution 11: An older persons' jury

Need: Awareness that help is available

Solution 1: Information bank

Solution 2: Training for staff

Solution 3: Work group of older people

Solution 4: Information centre for older people

Solution 5: Trained reception staff

Solution 6: Information packs for older people

Solution 7: Information packs about particular illnesses

Solution 8: Collaboration between organisations for older people and services supporting people from particular cultural groups

Solution 9: A social business register

Solution 10: Barter scheme

### Suggested solutions

Solution 1: Information bank

- centrally maintained and updated, for example in the library
- information gathered from all sources
- available to all organisations, and to older people themselves
- all services contribute changes to this bank

*(Continued)*

- information organised so as to provide a total picture of the services available to meet specific needs of older people

### Solution 2: Training for staff

- workshops available to all health and social care staff, including reception staff
- timetabled well in advance
- focus on identifying the total range of services available to meet specific needs of older people

### Solution 3: Work group of older people

- to review information provided by organisations and ensure it is user friendly
- to identify topics on which information is needed
- to identify ways of providing information so it is readily accessible to older people

### Solution 4: Information centre for older people

- an initial point of enquiry for older people
- drawing together information from the various organisations in Slough
- offering a help line, drop-in centre, and home visiting service
- the office base for a range of voluntary organisations working with older people
- employing people who could speak the main languages used by older people in Slough

### Solution 5: Trained reception staff

- to explore requests for information from older people
- to act as guides to the services their organisation provides
- to identify who can provide the necessary information, either within their organisation or elsewhere
- to provide help to ensure older people can access the service they need

(Continued)

### Solution 6: Information packs for older people

- detailing where in Slough you can obtain help and information
- information organised around specific needs
- delivered to older people as they reach pensionable age

### Solution 7: Information packs about particular illnesses

- detailing where help and information is available for older people with particular diseases, for example cancer or dementia
- distributed at the time of diagnosis

### Solution 8: Collaboration between services for older people and organisations supporting people from particular cultural groups

- sharing resources and expertise
- transmitting information to those whose first language is not English
- supporting people in their own community settings
- involve members of minority ethnic communities in Slough in decision-making about services

### Solution 9: A social business register

- to act as a directory of reputable trades people
- businesses meeting certain criteria would be invited to register
- businesses would pay to register
- businesses could be recommended by older people

### Solution 10: Barter scheme

- time swap or barter schemes, to obtain household or gardening assistance
- encouragement for older people to use current scheme in Slough
- help older people to identify what assistance they can offer in return for obtaining assistance with practical household tasks

(Continued)

### Solution 11: An older persons' jury

- twelve older people selected from the Citizens' Panel
- to debate topics of importance to older people, as suggested by Slough Older People's Forum and the Partnership Board
- to make recommendations about the funding of services to the Partnership Board

### Prioritising of solutions by the PWG

The research team took draft summaries of the needs and solutions to a PWG meeting. Solutions were set out on a series of cards – one solution per card – and PWG members were asked to work in pairs to put aside the solutions they thought least important, so eventually the remaining cards would be the solutions they most wanted. They debated the suggestions, but struggled to prioritise – saying there were too many solutions, but not wanting to discard any of them. By the end of the meeting, only two of the suggested solutions had been rejected: solutions 9 and 10. Slough already had a version of the barter scheme, a LETS token scheme, and this was not perceived as particularly relevant to the needs of older people. There was scepticism as to whether the Social Business Register could be successfully implemented.

Essentially, they wanted everything that was suggested, and tended to see a building (solution 4) as offering a base wherein all other solutions could be provided. There was however growing recognition of the difficulty of individual organisations all trying to maintain their own databases, and acknowledgement that a building would not of itself solve this problem.

### Suggestions from the PWG

The PWG members suggested that perhaps the main Slough library would be a possible host for a

single database that could be accessed by all services and older people themselves. Voluntary organisations already sent an annual statement to this library. At present the information being supplied by voluntary organisations did not get used to its full potential in the library. In addition, librarians were seen as professionals who had the skills to collate, maintain and update such a database, although again in relation to community and service information these skills were not used to their full potential.

It was thought that there might then be a number of outlets where such a database could be accessed: the suburban libraries as well as the main library, the council 'one-stop shop' to supplement the local authority information available there, and wherever the proposed health information centre is eventually sited. It could also be accessible within the suggested older people's information centre (solution 4).

It was also agreed that the next meeting of the Slough Older People's Forum would be devoted to a consideration of this project. Members of the Forum would be asked to decide which of the solutions they thought would be most useful for Slough.

### Meeting with the Slough Older People's Forum

The Chair of the Forum (also a PWG member) sent out notices of the meeting to the approximately 70 people on his mailing list, as well as asking the local media to publicise it. In addition, he notified members of the Partnership Board, the strategy group that underpins the council and health trusts' planning in Slough. The research team also circulated all those who had participated in the research project: this circulation had some areas of overlap with the chair's mailing list.

The Forum had been meeting in a room provided by the Slough Council for Voluntary Services. The room is comparatively small, which makes it difficult for the Forum members to break

into smaller subgroups for discussion or work groups. They had been looking for an alternative venue, but could not afford the high fees to hire many of the local halls.

The research team agreed to hire a larger hall for this meeting. Those who attended could be seated in small groups around tables, with the aim of facilitating discussion, and enabling people to work together. The aim was also to see whether a different venue might increase attendance, and if a different way of working within the meeting might enable informed decision-making.

Discussion of the project would be the only business of the meeting.

### The Forum meeting

Twenty-five people attended the meeting. They were mainly members of the Slough Older People's User Group, but some members of the Partnership Board and some voluntary sector service providers also attended. Since the meeting date coincided with the date of a national strike of local authority workers, there were no representatives from council services.

A reporter from the local paper covered the meeting.

The research team gave a very brief introduction and overview of the project, and then asked those present to consider the suggested solutions.

People sat around three tables, choosing for themselves whom they would sit with. Each group had an enlarged summary of the needs and solutions that had been identified (see box, page 14), and each person had a set of 11 cards, with each solution listed on a card.

They were first asked to discuss the solutions in pairs, and to draw on their own experience to decide which solutions they personally thought would be most useful, and which they thought would be least useful. They could organise the cards, setting aside those listing the solutions they found less useful, if that helped to make a decision. Following collection of their individual decisions, they were asked to discuss the solutions in their groups at each table, and come to an agreement about which solutions their group would most like to see in Slough, and which solutions would be least useful in Slough.

One person left the meeting midway through, after the break following the recording of individual preferences. He had a hearing impairment, and found that the background noise of the discussion meant he was unable to hear properly.

### Individual preferences

Those solutions chosen as most and least useful respectively are listed in Table 1.

It was apparent from discussion that, in the main, advantages could be seen for all of the

**Table 1 Individual preferences**

|                                                                                                                            | Frequency chosen |
|----------------------------------------------------------------------------------------------------------------------------|------------------|
| <i>Solutions viewed as most useful</i>                                                                                     |                  |
| 1. Information bank                                                                                                        | 16               |
| 4. Information centre for older people                                                                                     | 15               |
| 8. Collaboration between services for older people and the organisations supporting people from particular cultural groups | 9                |
| <i>Solutions viewed as least useful</i>                                                                                    |                  |
| 10. Barter scheme                                                                                                          | 13               |
| 9. Social business register                                                                                                | 12               |
| 11. Older persons' jury                                                                                                    | 9                |

suggested solutions. However, there were more polarised views around some suggestions than others.

There seemed to be consensus around the three suggestions preferred as most useful: no one chose either the information bank or the information centre as amongst the least useful, and only one person considered solution 8 (collaboration) as amongst the least useful. Of the solutions viewed overall as least useful, there was also a degree of consensus: no one chose the barter scheme as amongst the most useful, only one person chose the social business register as amongst the most useful, and three people chose the older persons' jury as the most useful.

There were more polarised views around the other five suggested solutions: for example,

solution 3 – the work group of older people – was chosen as amongst the most useful by three people and the least useful by four.

### Group preferences

The solutions chosen as both most and least preferable by each group are listed in Tables 2 and 3.

Group 1 were not able to agree on their third choice of most useful solution; their choices split equally three ways. Time expended on this heated debate meant that they did not decide on the least useful solution.

There was considerable agreement amongst the three groups, with their decisions broadly in line with individual preferences.

**Table 2 Group choice of most useful solutions**

| Group | Solutions viewed as most useful                                                                                                                                                                                                                                    |
|-------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1     | 1. Information bank<br>4. Information centre for older people<br>2. Training for staff<br>6. Information packs for older people<br>8. Collaboration between services for older people and the with organisations supporting people from particular cultural groups |
| 2     | 4. Information centre for older people<br>2. Training for staff<br>8. Collaboration between services for older people and the organisations supporting people from particular cultural groups                                                                      |
| 3     | 1. Information bank<br>4. Information centre for older people<br>6. Information packs for older people                                                                                                                                                             |

**Table 3 Group choice of least useful solutions**

| Group | Solutions viewed as least useful                                                                          |
|-------|-----------------------------------------------------------------------------------------------------------|
| 2     | 9. Social business register<br>10. Barter scheme<br>11. Older persons' jury                               |
| 3     | 7. Information packs about particular illnesses<br>9. Social business register<br>11. Older persons' jury |

## Groups' choice of most useful solutions

All three groups chose solution 4, the information centre for older people, wanting a clear point of contact for older people. However, it was seen that such a centre could not work without solution 1, the information bank. A comprehensive and regularly updated source of information was seen as essential for the centre, and thus the information bank was the first choice of two of the groups. The group that did not choose solution 1 did so because they regarded it as a necessary part of the information centre, and hence included within solution 4.

There was strong support for staff training, solution 2, from two of the groups.

*Staff training is vital, it makes such a difference.*  
(Older person)

*It's wrong to have to shout, the little girl at the end of the phone is not to blame. She hasn't been trained.*  
(Older person)

There was recognition that some thought had to be given to what could reasonably be expected of reception staff.

The support for this solution following group discussion was greater than appeared from the individual preferences, where solution 2 ranked equal fourth, chosen as amongst the most useful by seven people (and as amongst the least useful by three people).

Solution 8, collaboration, was also strongly supported by two groups, in line with the individual preferences.

*It is very important to know what people in Slough want, and to offer support in their own settings.*  
(Forum member)

The choice of solution 6, information packs for older people, by two of the groups was again slightly stronger than appeared from the individual preferences. Solution 6 was ranked equal fourth of the individual preferences, chosen as amongst the

most useful by seven people (and as amongst the least useful by three people).

## Groups' choice of least useful solutions

The groups' choices of least useful solutions largely followed the individual preferences. However, one of the groups included solution 7, information packs about particular illnesses, a solution that ranked fourth amongst individual choices of least useful solutions. Six individuals had selected it as amongst their least useful, while two people chose it as amongst the most useful.

The group that chose it as least useful had also chosen solution 6, a more general information pack, as amongst their most useful solutions. Thus they were not rejecting information packs, but were clear that they did not want information about illnesses. This reflected a desire for information covering a broad range of topics, not simply a narrow health and social care agenda.

There was scepticism about how a social business register (solution 9) might work. The rejection of an older persons' jury (solution 11) seemed to reflect widespread 'consultation fatigue', and perhaps also a feeling that it would not directly lead to better information.

Despite the suggestion of a barter scheme being relegated to amongst the least preferred solutions, there was considerable interest in the discovery that there was such a scheme currently operating in Slough. There was surprise to hear that it had been operating for at least 12 months, and persistent queries about why it was not better known:

*I can't understand how no one here knows about it.*  
(Older person)

The Chair of the Slough Older People's User Group had been unaware of the LETS scheme until it was mentioned at the PWG. (LETS stands for Local Exchange Trading Scheme, a national barter scheme based on an exchange of tokens.) While it was not declared at the Forum meeting, this

## Older people's perspectives

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widespread lack of awareness seems partly to result from an assumption that the scheme was not relevant to older people. This in turn appears to reflect assumptions about what older people might

offer to such a scheme, and require in return. Older people themselves did not share such stereotyped attitudes, and could identify what they might contribute to and gain from such a service.

# 10 Messages from Slough Older People's Forum

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Discussion at the meeting reinforced many of the earlier findings of this study. The discovery of the barter scheme highlighted the fundamental problem of becoming aware that there was information that could be useful: no one at the meeting had realised that they might obtain help with lawn-mowing, say, in return for baby-sitting. One of the service providers at the meeting wrote up a contact number for the scheme, and many people took down the details.

One service provider was concerned that the solutions referred only to information, rather than distinguishing information, advice and advocacy. This did not appear to be an issue for the older people themselves. However, different understandings of information were evident. Some people had a definition of information as a collection of facts that could be uncovered by diligent research:

*There's loads of information available. But no one's coming to your door to give it to you. You've got to find it out. There is endless information in leaflets, from organisations. (Older person)*

While this woman could readily be categorised as a self-seeker of information, as she listed the numerous sources of information she could tap into, her conception of information was akin to that of the information service provider (quoted on page 9) who saw himself as a 'mobile signpost': there is a body of knowledge out there, people just need to seek it out, or be directed towards it.

Another person at the meeting expressed a very different understanding:

*You're telling me how hard it is to get information! You can't get it out of them: I have to go and kick it out of them. (Older person)*

He was approaching agencies on behalf of other older residents in supported housing. He wanted to know when the agency was going to provide the

particular service needed by an older person. He talked of this process as getting information; it could equally be seen as taking on an advocacy role.

The understanding of information as part of a process leading to service provision was widespread, as was frustration with current services:

*If you make a telephone call, you get a young lady, and the best you get is another number .... (Older man)*

*... If you're lucky – mostly you get a recorded message telling you to press the star key, then to press a number, then you get the music – then you might get someone who passes you off with a number. (Older woman)*

The older man above continued:

*It sometimes does you good to get annoyed.*

recounting how he had successfully gained the service he required by getting angry when initially refused it. (He had phoned the council to enquire whom he could get to take away a bed frame that was no longer needed. The bed frame was a mixture of wood and metal; the council was prepared to take the metal, but not the wood.) However, he also was the person quoted earlier (page 19), acknowledging that it was wrong to blame 'the little girl' at the end of the phone, who was unlikely to have received the training she needed.

A clear message was that older people did not want information solely focused on health and social care, but on more positive leisure and volunteer activities to undertake once they had retired from paid employment.

*I like to think between the time you retire, and the time you need health and social services, there's 20 years. There's a lot of information you need about*

## Older people's perspectives

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*activities for mind and body. Part of the information we need to disseminate is about the dances and the clubs. (Older person)*

The council produces a free newspaper – the *Citizen* – that details local activities and clubs. It is supposedly distributed to each household monthly, but many of the older people at the meeting never received it. (There was a general belief that the people paid to distribute it – predominantly young boys – simply dumped the copies somewhere inconspicuous. The local reporter, remembering his own youth, confirmed this view.) Bulk copies were available at a number of town centre locations, but not at the Age Concern centre that a number of older people attended. They decided to ask that it be delivered there.

The meeting itself acted as a very good forum for the exchange of ideas and pooling of

information. But Slough lacks places where older people can meet:

*We haven't got the halls, or if they exist, they are too expensive. There is nowhere we can meet. (Older person)*

The hall we were meeting in illustrated this difficulty. It cost several hundred pounds to hire for the three-hour meeting. The older people remembered when it was a community centre, a venue for a wide range of clubs and activities available to local people at very little cost.

*I used to come here after work, to the dances. And they organised holidays, and we all went away together. There was painting and such for the children. You had to pay for the trips, of course, but just about everything else was free. Now we can't afford to come here. (Older person)*

# 11 Information, advice and advocacy

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Diverse interpretations of information, advice and advocacy have been a constant element throughout this study, whether in individual interviews, focus groups, or meetings. Sometimes the differences were hotly contested, as in the debates about the meaning of advocacy, but more often they were implicit and unacknowledged.

## Definitions

As a research team, we did not wish to impose definitions of information, advice and advocacy on the study, but to work with the definitions used by older people and service providers. However, the lack of familiarity with the term ‘advocacy’ amongst many older people meant we usually had to offer some clarification, to overcome the common assumption that it was a legal process. In such instances we would talk of advocacy as helping people make their case or to obtain their rights, to help make their voice heard.

Older people used information as an umbrella term, to cover all aspects of information, advice and advocacy. The distinctions between these services did not appear relevant: all were potentially part of a process that should result in them receiving the help they needed, or access to the service they wanted.

Service providers varied as to whether they saw information, advice and advocacy as services existing along a continuum, or whether they drew clear boundaries between them.

Those who drew clear boundaries were usually in specialist services, set up to provide either information or advocacy. Those who considered information, advice and advocacy as lying along a continuum were more usually based outside specialist information, advice or advocacy services: they offered information, advice and /or advocacy as an integral part of their service to older people.

*Information tells older people what they need to know, advice helps them chose what they want, and*

*advocacy helps them get what they want. It's along a scale. (PWG member)*

This notion of a continuum, or scale, does not account for what sometimes appears as a more circular process, whereby advocacy is needed to obtain information (Dunning, forthcoming). The older man who could only obtain information by going to ‘kick it out of them’ concisely expressed this more interactive understanding at the Forum meeting.

More fluid boundaries to service provision had obvious advantages in terms of providing a flexible service, responsive to the service users’ needs. But agencies could also pay a price if there were few limits to their task.

*Advocacy is what we do, but we do a lot of other things besides – the practical support and help, for example, to put the things in place that enable a hospital discharge. Because no one else is doing it. The boundaries of advocacy are very bendy. I would like clarity about what advocacy is, we can't keep filling all the gaps. (Service provider)*

As was previously noted (page 9) some service providers drew a sharp distinction between information and advice, and were careful not to be drawn into offering advice. There was a fear of litigation if you got it wrong, and a feeling that they did not have the necessary expertise to offer appropriate advice. Even those who saw more fluid boundaries between information, advice and advocacy were likely to offer advice only within what they perceived as their area of expertise. Expertise was an issue for some advocacy services also, especially if they were working with people who were unable to communicate fully their own wishes.

*My background is in [service X]. In those environments I'd feel reasonably able to say 'Well, that's not right, actually, and I know about this, so stop doing it or explain to me why you're doing it.'*

*But in another area, say cancer care, I wouldn't have a clue what is right or wrong, and I wouldn't feel at all comfortable going into a cancer ward of terminally ill patients and saying 'That's not right' because it could well be clinically proven best practice.*

(Service provider)

### Models of information, advice and advocacy

Different definitions of information, advice and advocacy reflected different models, especially for the provision of information and advocacy.

Service providers could be distinguished by whether they operated on a signposting or a sifting model of information provision (see page 9 for quotes from service providers illustrating these two models). The signposting model assumes the older person comes to the service knowing what they need to know; the sifting model assumes an initial request for information may not fully encompass or articulate what the older person needs to know. While this distinction was implicit in many discussions, the different models were not explicitly acknowledged.

The distinction between an empowerment and a closure model of information provision was explicitly acknowledged within the PWG (see page 9). The empowerment model assumes older people have the necessary skills and resources to obtain the service they want; they simply need to be given the information about who to contact. The closure model assumes that older people may not always have the energy and resources necessary to achieve a satisfactory resolution, and may need ongoing assistance.

Local debates about advocacy reflect the long-standing and widespread differences in the definition and development of advocacy services (Dunning, forthcoming). In Slough, a particular tension for services was whether they offered a representation or best interest model of advocacy provision. The representation model assumes the older person knows what they want, and at most

needs assistance to have their voice heard; it sees self-advocacy as the ultimate aim. A best interest model assumes that older people may not always be aware of what is in their best interests, or may not be able to communicate adequately what they want; it frequently operates on a long-term befriending basis.

A representative from an advocacy service which recruits volunteers to work with people with learning disabilities or long-standing mental illness expressed her reservations:

*Advocacy is about truly representing people's view. If someone can't tell you that, how do you go about it? So there's the whole debate about best interest. If people have dementia, say, you have to take an independent view. Can we put volunteers in a position where we are asking them to make judgments about what is happening in quite a sophisticated clinical setting? I do worry about this: what is advocacy and what is not. It is hard enough to get volunteers to understand that their views actually don't matter, it is the views of the person we are advocates for. Then [when someone is unable to fully communicate their views] in the next breath we are asking 'What do you think about that? Tell us what it's about'. It's hard: lots of conflict and dilemmas.*

(Service provider)

### Older people's views

The definitions and distinctions operated by service providers appeared of little relevance to service users, except in their practical consequences on the type of service they received.

For older people, the provision of information, advice and/or advocacy is inextricably linked to getting the service or resource they want. There were many examples where the information given was seen as without value, because it did not result in any such achievement, even if from the service provider's perspective they had successfully offered the appropriate information.

The members of the research team at first had found this link confusing. We were asking about information, advice and advocacy services in particular, yet were continually being told stories about accessing services in general. It took us some time to appreciate the extent to which information, advice and advocacy were seen as only part of a process of accessing services or resources. They were a means to an end.

There was also an example of this link operating in another way. In this instance, we had interviewed a representative of a walk-in centre at a hospital. She explained that her service was not appropriate for our study: they did not offer information. They offered treatment, on a drop-in basis, and predominantly over the short-term; for more long-term health problems, people were referred to their GP. Yet at the Forum meeting, an older woman was enthusiastically recommending the walk-in centre as an example of an excellent information service.

*The walk-in centre is very good. My GP is very busy, and there can be a long wait to get an appointment, and I don't want to bother the GP unnecessarily. I go*

*to the centre, you can just go without an appointment, and they'll tell you. They'll tell you whether you need to see your GP, or if it's something they can deal with, or doesn't need to be worried about. (Older person)*

From her perspective, the Centre offered an information service, advising her about whether or not she needed to go to her GP with a health problem. The centre staff drew a clear distinction between their treatment oriented service, and other health information services available; they held a particular model of an information service. It was not a model shared by the service user; from her perspective, information was a valuable element of the service being offered.

The concept of 'too much information' also reflected older people's views of information as a means to an end, not of itself intrinsically useful. What was useful was information tailored to their particular situation, and they valued the expertise of those service providers who could personalise the available information, as well as ensure they received information about all relevant resources.

# 12 The research process

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The process of doing the research sometimes mirrored that which we were studying.

## Documenting provision in Slough

One of our aims was to document current and proposed information, advice and advocacy provision in Slough. We soon realised this was not achievable. The rapidly changing nature of services, particularly within the voluntary sector, would make such a document out of date from the moment it was assembled. Over the 12 months we were gathering data, 5 of the 23 services whose representative we interviewed ceased to operate. Our difficulties here reflected the difficulties of both service users and service providers, both in becoming aware of what is available and maintaining that awareness over time.

We obtained suggestions of services to interview from initial interviews with groups of older people, also from PWG members. Despite this assistance, contacting service representatives and arranging to meet could be time consuming: the difficulty in getting an answer when telephoning, or being transferred to the correct person, mirrored some of the difficulty older people had in getting through to hard-pressed services.

Our efforts to identify relevant information, advice and/or advocacy services were assisted by the PWG and a range of contacts in Slough. Nevertheless, it was only at the end of the study, following a newspaper report on the Forum meeting, that an agency contacted us to say they should have been included in the study. This was a voluntary sector agency, offering what they describe as 'holistic advice' to older people, highly relevant to our research. This incident underlined the difficulty that an older person in Slough might have, in becoming aware of the full range of relevant services.

There was also a fundamental problem: whose definition of information, advice and advocacy should we use? The agencies? The service users? Information, advice and advocacy professionals? Each would result in a different listing of services.

## Cultural competence

We wished to obtain the views of older members of the South Asian communities of Slough. These communities are heterogeneous, differing along dimensions such as country of origin, language, religion, age, gender, class and education. Community leaders express strong views as to the perspectives and needs of their respective communities; individual members may hold different, but less widely promulgated, views.

The research team were all white women, none of whom spoke any of the languages of the South Asian communities. Our difficulties in obtaining the perspectives of older members of Slough's South Asian communities had parallels in the efforts of predominantly white service providers attempting to offer appropriate services to members of these communities, and of the Older People's Forum trying to encourage wider membership from the ethnic communities.

We therefore hired as research assistants translators who spoke the main languages of the communities, informing them of our aims and providing a broad outline of the topic areas we wanted to cover. They came with us to visit the community groups following personal introduction from community workers, and they conducted the group interviews with older people from the South Asian communities in their community settings.

The research assistants, themselves members of South Asian communities, had either a health promotion or community development background. They saw the interviews as an opportunity to raise awareness about the

information available. However, it was difficult for us to know to what extent they were equally acceptable to all communities, and thus how readily older people would disclose their views.

The period of our study included phases of increased tension for members of the South Asian communities. The attack on the World Trade Centre in New York, and subsequent assaults on Muslim societies in revenge left all feeling vulnerable: hostile people were not necessarily able, or willing, to distinguish Muslims from other South Asians. The increased tension on the national stage between India and Pakistan over Kashmir also had an impact locally.

### Involving older people

The aim of the study was to involve older people in all aspects of the research. We wanted 'true' involvement, neither manipulative nor tokenistic. The older people on the PWG, perhaps understandably, did not appear particularly interested in close involvement with the project until we had the findings to report. It was a reminder that the right to be involved did not mean that there was an obligation to be involved. Once we started to present findings, however, the PWG considered their meaning carefully, and worked at clarifying and elaborating their significance.

We also struggled to recruit enough older people for the individual interviews: we interviewed 13 people rather than the 20 originally proposed (and consequently increased the number of group interviews). This was despite appeals for participation via the media and professionals working in Slough. Some service providers similarly struggled to gain access to older people.

*A lot of people we'd like to offer our service to can't themselves get in touch with us. We rely on the people who provide services to refer them to us. It is sometimes frustrating because we can't quite get to the people who most need our services.*

(Service provider)

A key issue for the Slough Older People's Forum was how its membership could become more representative of all Slough's older people, and how older people could become more fully involved in decision-making. There was frustration at what could be seen as a 'top down' approach, with information-giving and hasty consultation offered instead of participation. We wished to avoid such an approach at the meeting we attended, and were keen to model ways in which older people could be involved in decision-making. However, one of the people at the Forum commented that he would have welcomed information about the suggested solutions in advance, so he had more time to consider them:

*At meetings like these, you never get information in advance. Then the papers come, and you have to comment, and I just say what comes into my head, instead of thinking about it properly. You all do it!*

(Older person)

We had deliberately kept any paperwork to a minimum, and wanted people to have a chance to discuss issues together – but clearly, he still felt rushed to a decision.

The need for time to reflect on written material was also evident within the PWG. It was noticeable that some members of the PWG had swiftly reached a decision, while others were still debating and exploring the issues involved.

# 13 Conclusion and recommendations

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Older people experience many barriers in accessing information, advice and advocacy. The most fundamental perhaps is a lack of awareness that there is a possible service or resource that would be useful to them, so they do not seek out information about it.

Older people want accurate information, and information that is comprehensive, i.e. information provided on all possible relevant resources. The emphasis here is on relevant information: too much information, not tailored to their own particular needs, was as bad as too little information. While these may seem reasonably modest expectations, this study found evidence of the difficulty services experienced in providing accurate and comprehensive information. Services lacked the resources to develop and maintain co-ordinated information databases.

There is no one solution that could meet all the needs expressed by the various older people of Slough. However, older people and representatives of organisations of and for older people in Slough prioritised some suggested solutions. The two most preferred options were:

- 1 An information bank, to provide co-ordinated and updated information for the information providers, as well as the basis for user-friendly and comprehensive information for older people.
- 2 An information centre for older people, to provide a point of contact and a place where information, advice and advocacy can readily be accessed. It would incorporate the information bank.

## Recommendations

Services in the statutory sector have recognised the importance of information provision. Both Slough council and local health trusts are required to provide information to service users. It is therefore recommended that, instead of separately providing

information around relatively narrow service definitions, the statutory sector works with the voluntary sector to set up, and subsequently maintain, a co-ordinated and comprehensive database, accessible to both service providers and service users. The library could be considered as the host for such a database.

The database needs to be fully accessible to a wide range of agencies, and their information contributed to it. It also needs to be accessible to older people – and thus distributed as widely as possible throughout Slough.

The database should be responsive to older people's desire for information and advice about broad quality of life issues, including leisure activities.

It could also form the core of an information centre for older people, which would provide a high profile point of contact for older people to access information, advice and advocacy services. It is recommended that the statutory sector services, rather than set up their own separate information resource centres, work in partnership with the voluntary sector to provide a more comprehensive information centre for older people. Again, it would be important for such an information centre to offer the broad range of information desired by older people, and not just follow an illness and infirmity agenda. The proposed redevelopment of the central area of Slough, 'The Heart of Slough', offers an opportunity to site such a resource within the town centre.

There are currently a range of initiatives planned for Slough: the local primary care trust has developed a communications strategy for working with ethnic communities, and the Partnership Board has produced a strategy for older people alongside a health improvement plan for the next ten years. A co-ordinated approach to implementing these three major programmes offers the opportunity to meet many of the needs identified by this research.

# 14 Methods

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A Project Working Group was set up, comprising representatives of seven organisations in Slough, including those run by and those for older people (see Appendix 1), plus the three-person research team from the University of Reading. Membership of the PWG fluctuated throughout the research period.

## Research aims and objectives

The aim was to draw on the experience and expertise of older people, and of the relevant voluntary and statutory agencies, to discover what older people would value from information, advice and advocacy services, and appropriate models for the delivery of such services.

The PWG planned to work with older people and service providers to clarify:

- what information provision is currently available, and how this is viewed both by users and by those older people not availing themselves of it
- what type of information and advocacy provision older people would most value
- the most appropriate means of providing such information, from older people's perspectives.

## Preliminary stage

Approval was gained from the University of Reading Research and Ethics Committee, and the East Berkshire Community NHS Trust.

A Project Advisory Group was set up, chaired by a representative of the Joseph Rowntree Foundation; members are listed in Appendix 2.

## Research stage 1: perspectives of service providers

Key organisations providing information, advice and/or advocacy services in Slough were identified via:

- recommendations from PWG members
- meetings held with groups of older people to obtain their suggestions as to key providers
- recommendations from informants, once interviews commenced.

A total of 23 key informants, representatives of services providing information, advice and/or advocacy, were interviewed.

## Research stage 2: models of good practice developed

Identification of good models for providing information, advice and advocacy via:

- literature review
- meetings with service providers
- interviews with key informants
- Project Advisory Group members.

These models were explored in the interviews with older people.

## Research stage 3: perspectives of older people

A sample of older people was identified via:

- key informants and members of PWG asked to give out information packs to service users, and request their participation
- health and social care professionals in Slough asked to publicise the study, and request participation
- colleagues of the University team members asked to publicise the study amongst any older friends or relatives living in Slough
- request for participants made on local radio
- requests made to individuals attending group meetings.

## Older people's perspectives

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A total of 13 individuals were interviewed, with an age range from 55 to 91.

Group meetings were held with older people:

- members of minority ethnic communities at Milan Community Centre and Sangham Day Centre Carers' Group
- Colnbrook Luncheon Club; Wexham Social Club, and Carers' Forum.

Approximately 120 people participated in these group discussions.

The older people included those who had not used any of the 23 services from which we interviewed a representative, through to one who had used five of the services.

### **Research stage 4: solutions prioritised**

Suggested solutions to meet the needs for information, advice and advocacy services in Slough, and for appropriate means of involving older people in the development of such services were identified via:

- literature review
- meetings with service providers
- Project Advisory Group members
- interviews with key informants
- interviews with older people.

Members of the PWG made an initial attempt to prioritise these solutions, and in the process elaborated them further.

The solutions were then taken to a meeting of the Slough Older People's Forum, and their preferred solutions identified.

# References

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Barnes, M. (1997) *Cave, Communities and Citizens*. London: Longman

Cabinet Office (1998) *Better Government for Older People*. London: HMSO

Carter, T. and Beresford, P. (2000) *Age and Change*. York: Joseph Rowntree Foundation

Dunning, A. (forthcoming) 'Information, advice and advocacy for older people'

O'Keefe, E. and Hogg, C. (1999) 'Public participation and marginalized groups: the community development model', *Health Expectations*, Vol. 2, pp. 245–54.

# Appendix 1

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## Original members of the Project Working Group

Names and organisations are recorded as at the time of making the bid for project funding: September 2000.

|                  |                                                                                 |
|------------------|---------------------------------------------------------------------------------|
| Chris Commerford | Age Concern Slough                                                              |
| Jo Hawthorne     | Slough Council for Voluntary Services, and Community Care Forum Liaison worker  |
| Ann Luttrall     | Alzheimers Disease Association, and Carers National                             |
| Christine Parker | Age Concern Slough                                                              |
| Surinder Ratan   | Community Development Worker, Slough Borough Council                            |
| Naomi Ridley     | Age Concern Slough                                                              |
| Sally Thompson   | Slough Carers' Association                                                      |
| Jim Whittaker    | Chair, Slough Older People's Forum, and Chair, Slough Older People's User Group |

The University of Reading team:

|                 |                                |
|-----------------|--------------------------------|
| Pam Denicolo    | School of Education            |
| Ann Quinn       | School of Health & Social Care |
| Angela Snowling | Berkshire Health Promotion     |

# Appendix 2

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## Members of the Project Advisory Group

|                 |                               |
|-----------------|-------------------------------|
| Alex O'Neil     | Joseph Rowntree Foundation    |
| Gillian Crosby  | Centre for Policy on Ageing   |
| Andrew Dunning  | The Beth Johnson Foundation   |
| John Edwards    | Age Concern England           |
| Su Harnett      | Slough Primary Care Trust     |
| Maureen Pope    | The University of Reading     |
| Brenda Williams | Older people's representative |
| Mike Woolridge  | Wokingham District Council    |

