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# Scoping Review on Access to Information about Social Care Services

**Kate Baxter, Caroline Glendinning and Sue Clarke**

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# Executive summary

## Background

This report is a response to a recommendation in 2004 by the Better Regulation Task Force that the DH should commission research on people's experiences of the availability and accessibility of information on social care services. The government accepted the recommendation and agreed to commission a review of evidence to establish what is required in terms of future research. SPRU was commissioned to undertake a scoping review of available evidence, as part of the responsive research responsibilities that lie within its DH programme funding.

## Objectives

The purpose of this review was to identify gaps in knowledge and government activity that could be filled through future commissioning of research on people's experiences of the availability and accessibility of information about social care services.

The objectives were to:
- determine what work was in progress in government departments;
- undertake a limited review of the research evidence;
- identify any gaps where new research might be needed.

## Methods

The project was carried out between January and June 2006. A project advisory group, including representatives from the Department of Health and the Office for Disability Issues, met three times during the project. The project comprised three parts.

In part one, members of the project advisory group identified a number of government projects and initiatives under way in relation to the accessibility of information about social care services. The people involved in these projects and discussions became the starting point for identifying other government and government-related contacts and projects. Whilst the majority of discussions took place with staff based in government departments, some also took place with staff from government agencies and other organisations. These discussions were with staff involved with relevant projects that had been commissioned by government departments or were being carried out by government agencies, such as the

Commission for Social Care Inspection (CSCI). A total of 42 contacts were made. Each contact described the research and development projects that they were aware of, that related to the accessibility of information about social care services. For each project identified, a short summary of the main aims was compiled.

In part two, these short summaries were used to identify gaps in government research and development activity. A limited scoping review of recent published and unpublished literature was undertaken to try to fill these gaps. The review was restricted to studies from 2000 to the present about information needs of service users and the accessibility of information on social care services in England.

In part three, telephone interviews were held with information or helpline managers from six voluntary sector organisations. The purpose was to elicit their perceptions of the kinds of information people want about social care services and how accessible it is and, in particular, any gaps in the information that is available.

## Summary of results and conclusions

We identified 47 government-related projects that are aiming to investigate or improve the accessibility of information about social care services. Eleven are research projects to investigate the information needs and accessibility of information about social care services for users and/or carers. Thirty-six are development projects aiming to improve the accessibility of information about social care services. In addition, our literature search identified 18 articles that investigated, at least in part, the information needs and accessibility of information on social care services for users and carers. Telephone interviews with representatives from six voluntary organisations provided further information about the accessibility of information about social care services and gaps in the information available.

Many development projects (Section 64 funded projects in particular) do not appear to have an evaluation element. Therefore, even when these development projects are completed, they will not provide evidence on the effectiveness or appropriateness of the methods that they have been developing of providing information and improving its accessibility.

The government-related research projects and the research papers identified from the literature highlighted the information needs and problems in accessing information that some groups of people have. Whilst many of the government development projects identified were already addressing these issues, some information accessibility issues were not yet being addressed. The gaps in known information needs that are not being met are the specific information needs and accessibility issues associated with people from black and minority ethnic communities; with chaotic lifestyles (such as people who have just left prison or are drug or alcohol users); with fluctuating support needs; with visual impairments; with multiple impairments; and who are private purchasers of social care services.

In addition, there is little or no knowledge available from government research projects or from the recent literature on the accessibility of information about some types of social care services. We have no details about the accessibility of information about short breaks and respite care; day care and daytime activities; or equipment and assistive technologies. (Some development projects, however, are aiming to increase access to information about equipment and assistive technologies.) Research is therefore needed to fill the knowledge gaps in these areas.

Many development projects are aiming to develop one stop shops. The internet appears to be the dominant form of one stop shop. Internet-based information sources have many advantages: they can be updated quickly and efficiently; they can be accessed at any time and from any computer; and they can include large databases of information that cover all parts of the country. However, they also have their disadvantages: not everyone who needs the information has access to a computer; some people are not proficient in the use of the internet; and for some people their impairment makes using a computer without additional support difficult.

In addition, whilst many development projects are aimed at specific groups of service users (for example people with dementia or people with visual impairments), many people have dual or multiple support needs. These multiple support needs translate into multiple information needs. It is important therefore that people are able easily to access information for different needs and about different services. Thus the importance of providing information in a number of formats and across a broad range of user ‘categories’ is evident.

Several research studies concluded that older and disabled people wanted information from professionals and also wanted to use existing health and social care service organisations as information points. However, few development projects are aiming specifically to introduce or enhance information services in health care clinics or social care facilities. Although this review did not investigate information-related training for professionals, few of the development projects identified include an element of staff training. The collection of evidence about the role and effectiveness of professionals in imparting information about social care services and, if necessary, training to improve professionals’ ability to impart such information effectively, is important; they are often the gatekeepers to new services, but may not be knowledgeable about those services outside their direct remit or provided by other organisations.

It is not clear for many research and development projects whether the information needs of people who purchase social care services privately have been addressed.

This is a substantial group of people, including older people considering residential or domiciliary care and those people with assets that preclude them from receiving social services financial support. Research evidence has highlighted confusion about the liable relatives rule for residential care and a lack of information about fair charging for domiciliary care. Although one development project will help to plug this gap by providing explanations of the legal position on charging for community care services, further research on the accessibility of information for private purchasers is needed.

## Recommendations

One of the aims of this scoping review was to identify any gaps in knowledge or government activity where future research might be needed. This section highlights these areas.

There is currently no research evidence on the accessibility of information about:
- short breaks and respite care;
- day care and daytime activities; and
- equipment and assistive technologies.

Research on the accessibility and use of information should be undertaken in these areas.

Information needs for the following groups of people have been identified but are not yet being addressed by government development projects:
- people from ethnic minority communities, especially older people and carers;
- carers from rural communities and young carers;
- information for people with multiple impairments;
- people with fluctuating support needs, such as disabled parents, before they reach crisis point;
- prison leavers at the time of their release and other people with chaotic lifestyles;
- private purchasers of social care services (including the need to increase the accessibility of information about free social care services and information about help towards paying for services privately).

The following formats and methods of providing information have been identified as helpful or desirable by service users and their carers, but are not currently being implemented in development projects:
- support in using the internet for people with visual impairments or chaotic lifestyles;
- the provision of verbal information for people who are visually impaired or whose literacy levels in English or other languages are poor;

- better signposting of information sources, in particular information about where and how to start in finding out about social care services;
- personalised information in areas other than health care, equipment and housing services;
- the provision of information by social care staff and other professionals; and
- the use of positive case studies and inspirational stories from disabled people.

# 1. Introduction

In its report *Bridging the Gap – Participation in Social Care Regulation*, the Better Regulation Task Force (BRTF) recommended that: ‘by April 2005, the Department of Health (DH) should commission research on people’s experiences of the availability and accessibility of information on the range of social care services available to them (including voluntary and informal services). The aim should be to establish a single, accessible point of information’.

The government responded in December 2004 by accepting the recommendation and agreeing to commission a review of available evidence in order to establish exactly what is required in terms of future research that looks at information for service users across the whole spectrum of adult social care. The Social Policy Research Unit (SPRU) at the University of York was therefore commissioned to undertake a scoping review of available evidence as part of the responsive research responsibilities that lie within its DH programme funding.

Within government departments, particularly the DH and to a lesser extent the Department for Work and Pensions (DWP) and the Office of the Deputy Prime Minister (ODPM, now the Department of Communities and Local Government (DCLG)), a number of current initiatives that included information about social care services had already been identified. The extent to which these initiatives overlapped or where there were gaps in knowledge was not known. The report that follows therefore maps these and other government initiatives alongside recent evidence from a limited scoping review of the literature.

The purpose of this review is to identify gaps in knowledge and government activity that could be filled through future commissioning of research on people’s experiences of the availability and accessibility of information about social care services.

Social care services and the role of local authorities in the provision of those services are changing. Social care in the green paper *Independence, Well-being and Choice* is defined as ‘the wide range of services designed to support people in their daily lives and help them play a full part in society’ (DH, 2005: 24). Whereas, in the past, social services have been perceived as fostering dependence rather than independence, in the future, the aim of social care is to create an environment which supports individuals to take control of their own lives and to make the choices which matter to them (Prime Minister’s Strategy Unit, 2005). In general, there is a move away from the traditional range of social care services towards greater diversity in support arrangements and greater choice in how support is delivered. Information is crucial in achieving this empowerment, control and choice.

## 1.1 Aims and objectives

The aim of this scoping study was to review the range of, and identify gaps in, government and other recent research projects, and in government development projects, that aimed to investigate and/or improve accessibility of information about social care services for service users and carers across the whole spectrum of adult social care; and, if appropriate, to identify areas where new research might be needed.

The objectives were to:

- determine what work was in progress in government departments to:
    - *investigate* the accessibility of information about social care services to current and potential users and carers; and
    - *improve* the accessibility of information about social care services to current and potential users and carers.

- undertake a limited review of the research evidence on the accessibility of information on the range of adult social care services. Specifically, to identify research evidence on:
    - what information about adult social care services people want and need;
    - the accessibility via current access arrangements of information about adult social care services.

- identify any gaps where new research might be needed.

## 1.2 Scope and limitations of the study

This research was limited due to time and financial constraints. It has been carried out between January and June 2006. It considered only information about social care services in England which social services departments have traditionally been responsible for funding. These services include: residential care; domiciliary care; respite care; day centres and daytime activities; provision of equipment; support for intermediate care; information and advice centres; and housing adaptations and support.

The majority of social care is provided by informal carers, that is, families and friends. This type of care is not a service about which information can be provided. However, it is important to consider the accessibility to informal carers of information about other social care services, both those directed at carers themselves and those aimed at the person being cared for. Carers may also be important information intermediaries. The study therefore included the provision of information to users and informal carers. It considered information for people with physical and mental impairments, people with learning difficulties; drug and alcohol users, people with HIV and AIDS, older people, and black and minority ethnic groups.

The BRTF recommended research on both the availability and accessibility of information. Whilst information is available if it has been collected and presented for dissemination, it is accessible only if potential users are aware of its existence and are able to retrieve and understand it. The focus of this research was therefore on the accessibility of information. Information must be physically and cognitively accessible, that is, users must be able to find, retrieve and understand the information. Accessibility requires also that information is timely, easy to use and in appropriate formats. For example, information that is available only on the internet is not accessible to people without internet access; information that is printed on leaflets in English is not always accessible to the visually impaired, to people who do not understand English and those who cannot read.

Services can be provided by the public, private, formal/voluntary and informal sectors (Knapp *et al.*, 2004). It is important to consider also the availability of information to users who receive direct payments and those who pay for some or all of their social care services. This review therefore included information aimed at users and carers about social care services:

- commissioned by local authorities;
- which an individual or family organise and commission themselves, for example through direct payments, individual budgets or personal finances;
- provided directly by local authorities;
- provided by private and voluntary providers.

It excluded:

- initiatives aimed primarily at informing social care managers and front-line staff;
- information for employers about support for employing people with social care needs.

# 2. Methods

The scoping review comprised three distinct parts:

1. The first mapped and identified gaps in both research and development projects undertaken by government departments.
2. The second attempted to fill the gaps identified by the mapping exercise in part one by scoping recent published and unpublished literature in those areas.
3. The third part comprised a small number of telephone interviews with key voluntary organisations to elicit their perceptions of difficulties in accessing information.

## 2.1 Part One: Mapping and identifying gaps in government research and development projects

The aim of this section of the scoping review was to map initiatives within government that aimed to investigate and/or improve access to information. We defined initiatives to investigate access to information as research projects that aimed to explore people's information needs and wants as well as how accessible they found information. We defined initiatives to improve access to information as projects that were developing or implementing new ways of making information more accessible.

A project advisory group of staff from the DH, the Office for Disability Issues (ODI) and SPRU was set up. This group met three times: for initial planning of the study in October 2005; development and discussion of the proposal in January 2006; and to give feedback on interim findings in March 2006. The members of the advisory group identified a number of projects and discussions already under way in relation to the accessibility of information about social care services. The people involved in these projects and discussions became the starting point for identifying other government and government-related contacts and projects.

Face to face discussions were held with 11 key contacts in February and March. These contacts were asked to identify additional contacts who may be working on related initiatives. Whilst the majority of discussions took place with staff based in government departments, some relevant projects had been commissioned by government departments or were being carried out by government agencies, such as the Commission for Social Care Inspection (CSCI). These contacts were also asked for project details. Using this snowballing method, a further 31 contacts were made. Telephone discussions were carried out with the majority of new contacts in March and April. Some contacts gave information via email. A full list of contacts is given in Appendix 1.

All face to face and telephone discussions were tape-recorded. The recordings were not transcribed in full but detailed notes were made from them.

The discussions in the interviews aimed to:

1. elicit details of government research projects to investigate the accessibility of information about adult social care services;
2. elicit details of government initiatives or policy developments to improve access to information about adult social care services;
3. obtain the contact details of other departmental contacts who may have knowledge of the above.

For each investigation or policy initiative identified, respondents were asked to describe: the aims of the project and any relevant findings; its scope (which user groups, what services, what formats of and methods for disseminating information); and the timescale of the project/initiative. The checklists given in Appendix 2 were used as prompts to ensure that investigations and initiatives about information for all types of services and all user groups were considered in the discussions. Some respondents provided written summaries to supplement the verbal information provided. Every attempt was made to elicit the same information about each project from each departmental interviewee. However, as many respondents were overseeing a number of projects but not necessarily undertaking them, the information provided about some projects was more detailed than others.

Written summaries were made of each project identified through these interviews. The summaries included: a project title; start and end dates; the organisation or department undertaking the work; and a bullet point summary of the project aims and, where relevant, main findings. These summaries were sent to the departmental contacts who had originally provided the information to be checked for accuracy. In many cases, more than one contact had provided details of a project; summaries were sent to each contact for checking. Where amendments to the summaries were suggested, these were made. The finalised summaries were listed according to department, project type (research/investigation or development/implementation) and timing (recent, current or planned). Recent projects have been defined for this study as those that were completed or reported in 2005.

## 2.2 Part Two: Scoping the literature

Where the mapping exercise of government investigations and initiatives identified gaps in activity, a limited scoping review (Arksey and O'Malley, 2005) of recent published and unpublished literature was undertaken. This was not a systematic review of all relevant evidence. The aim was to map, rapidly, research evidence on topic areas not already being investigated through government research. The review was limited to studies from 2000 to the present about information on social care services in England.

Gaps in government activity were identified by categorising, by user group or service type, each project identified in part one. These were the same user groups and service types used in the interview checklists. We defined a gap in activity as existing when, for a user group or service type, there were no government research projects identified that were aiming to find out about the information needs or accessibility to information. For example, no government projects were identified that were investigating the information needs of people with HIV/AIDS. The literature was therefore searched for any articles that described the information needs of people with HIV/AIDS. Gaps in research activity for five user groups and five service types were identified. These are: BME groups; people with HIV/AIDS; people with mental health problems; people with sensory impairments; drug or alcohol abusers; day centres/day time activities; domiciliary care; equipment/assistive technology; intermediate care; and respite care/short breaks.

Articles were searched for on three electronic databases relevant to social care. Two were databases of published literature, namely Social Services Abstracts and Applied Social Sciences Index and Abstracts (ASSIA). The search was limited to these two publications databases due to time constraints. Unpublished literature and research in progress were included through a search of a third database, Social Care Online, which is managed by the Social Care Institute for Excellence and includes information and research on all aspects of social care. Exploratory searches on SIGLE (System for Information on Grey Literature in Europe), NRR (National Research Register) and ReFeR (Research Findings Register) during the development of the project showed that they do not produce relevant papers on social care services in England. They were therefore excluded.

The search terms were based on the checklists used in the discussions with government contacts. Three sets of search terms were developed and combined to find articles with at least one term from each set in the article’s title, abstract or key words. The sets related to the ten topics identified as knowledge gaps (set 1), information provision (set 2), and social care services (set 3). Terms were truncated as appropriate. Appendix 3 gives details of these terms. The same terms were used to search all three electronic databases.

The results were exported to an EndNote bibliographic management system, and duplicate references removed. Two people read the articles’ abstracts to identify them as potentially relevant or not. Potentially relevant articles were retrieved by means of electronic downloads if available, or from the University library or interlibrary loans. Empirical studies only were considered; theoretical and opinion papers were excluded. The abstracts and results sections of the potentially relevant papers were read. Those actually relevant to the study were selected for inclusion.

Appendix 4 shows the number of articles identified from each database, how many were potentially relevant, and how many were actually relevant and therefore included.

Details on information needs and accessibility from the included papers were recorded in a table. There was no attempt to summarise other sections of papers, such as methods or relevance of research questions. The papers were not subject to rigorous assessment of quality; publication in a peer reviewed journal was used as a proxy for good quality. Where papers have not been published in a peer reviewed journal, this has been noted in the text. Few articles focused specifically on information about social care services. Most included only a few sentences as part of a wider set of results, often about health care. The data recorded from the articles are therefore not shown in a separate table as they would be in a systematic review, but are presented in narrative form alongside the findings from the government and voluntary sector interviews.

We had anticipated hand searching recent copies of the most frequently cited journals to see if the search strategy was missing any relevant articles and to identify new articles not yet entered onto the electronic databases. However, articles were found from a diverse range of journals and there was no single most cited journal. We did not therefore hand search any journals. The reference lists of selected articles were searched for recent articles they had cited. These did not produce any new articles.

The number of government contacts and projects identified for part one of the study was greater than anticipated and therefore took longer to complete than expected. As a result we were not able, within the time constraints of the study, to contact members of *ripfA* (Research In Practice For Adults) or MRC (Making Research Count), as suggested in the study proposal. *ripfA* is a research utilisation organisation that aims to promote the use of evidence-informed practice in the planning and delivery of adult social care services. MRC is a consortium of universities aiming to bring researchers and practitioners together to improve the dissemination and implementation of research findings.

## 2.3 Part Three: Telephone interviews with voluntary organisations

Telephone interviews were held with information or helpline managers from each of a small number of key voluntary sector organisations. The purpose was to elicit their perceptions of the kinds of information people want about social care services and how accessible it is and, in particular, any gaps in the information that is available. The views provided were based on the experience and responsibility of respondents for managing information provision. Interviews were tape recorded but not transcribed in full. Instead, summaries were made of the main points raised. These are reported alongside the findings from the government projects and literature searches.

The voluntary organisations chosen were mainly large national organisations. In addition, one was suggested by the project advisory group and another by a consultation group that advises SPRU researchers on its research programme for adults and older people. Although each voluntary organisation represented a particular user group, they were not necessarily a representative sample. Nine voluntary organisations were approached, representing the following user groups: people with mental health problems; people with learning difficulties; people with sensory impairments (visual and hearing); people with long term/neurological conditions; drug and alcohol users; people with HIV/AIDS; older people; and carers. Six interviews were undertaken. Between five and seven attempts were made to identify and arrange telephone interview times with managers from three other organisations representing people with learning disabilities; sensory impairments (deaf) and people with HIV/AIDS. These three voluntary organisations were not able to identify anyone able to help within the timescale of the study. A list of the organisations from which an information manager was interviewed is given in Appendix 5.

# 3. Results

This section sets out the findings from the discussions with government departments about government-related research and development projects, searching of the literature for published articles about peoples' information needs and the discussions with a sample of voluntary organisations.

A list of the titles of government projects by department is given in Appendix 6. A fuller list of projects giving title, dates, a brief summary of aims, and whether or not there is an evaluation of implementation projects is given in Appendix 7. The projects are arranged by government department; whether they have been completed recently, are current or planned; and whether they are research/investigation projects or development/implementation projects. Each project is identified with a project identification number ranging from (1) to (12) for research projects and (13) to (47) for development projects.

Many government projects (both research and development) do not relate specifically to one user group or type of service; they are more generic in that they are attempting to increase the accessibility of information more generally. The projects that are described in the different categories of user group and type of service below are those that explicitly state in their aims that they either include or focus specifically on information issues for that category of user or service. This does not mean that other more general projects are not dealing with information issues for these groups, but that specific evidence, detailing which groups and how information issues relating to them in particular are being addressed, has not been provided.

The first part of this section presents findings for each user group and each type of service identified in the original proposal. The user groups are:

- Older people
- People with long term conditions
- Physically disabled people
- People with learning difficulties
- People with mental health problems
- Black and ethnic minority (BME) groups
- People with HIV/AIDS
- Drug and alcohol users
- People with sensory impairments
- Carers/informal providers.

The service types are:

- Residential care
- Domiciliary care

- Respite care
- Day centres/daytime activities
- Intermediate care
- Provision of equipment (including assistive technology)
- Advice and information centres.

The second part of this section includes details of projects aimed specifically at user groups or services not included above (for example, disabled parents).

The final part of this section describes all the other projects that are not user group or service-type specific.

In each category, the evidence is presented first on people's information needs as identified from government research projects and/or the literature, followed by details of government development projects that are addressing these and other information needs, and finally by any gaps in information provision and access to information identified by voluntary organisations. References to published articles are reported in the usual manner (for example, Robinshaw and Evans, 2002) and listed in Appendix 8. Government projects are cited by their project identification number given in brackets. Each category begins with a list of the number of government-related research projects, published articles and government-related development projects identified and discussed in that category. The list also shows whether a voluntary organisation was contacted.

## 3.1 Information needs and accessibility of information for different user groups

### *3.1.1 Older people*

| | |
|---|---|
| Government-related research projects | 3 |
| Published papers | 0 |
| Government-related development projects | 9 |
| Voluntary organisation interviewed | 1 |

Three government research projects have recently investigated the information needs of older people. Nine are currently developing or implementing new ways of improving access to information by older people. One further project is planned and will pilot the integration of local services (including information) for older people. The large number of government projects relating to information has meant that the literature was not searched in this category. A voluntary organisation was interviewed about gaps in the provision of information; a summary of these perceived gaps is included at the end of this section.

The three projects that investigated the information needs of older people have been completed. One project (6) investigated the potential of UK Online Centres to support the delivery of e-government services to users, including older people. E-government services include information about rural services and using Directgov. UK Online Centres aim to provide everyone in the UK with access to computers near to where they live, as well as help and advice on using them. They are community based - they could be in an internet café on the high street, in a public library, a college, a community centre or a village hall; some are mobile. They have been designed to meet the needs of local people who would otherwise not have access to computers.

Second, the Social Exclusion Unit Interim Report 'Improving Services, Improving Lives. Evidence and key themes.' (7), forms part of a programme of work that aims to make public services more effective for disadvantaged people. Although the project focused mainly on other welfare areas, it did look briefly at social care and has a chapter on information and communication.

The third research project was commissioned by the Commission for Social Care Inspection (CSCI) to investigate the types of media used by, and satisfaction with information available on care services to, older people (12).

Findings from these three research projects suggest that information can be hard to find by older people and difficult to understand; it may be unavailable, inaccessible or inappropriately marketed. Whilst large type, an easy to read style and video formats were welcomed by older people (12), the use of new technologies was suggested as a compliment or alternative to traditional text-based products (7). With appropriate training and support, the number of people, including older people, using online services and accessing information online could be increased (6). Better signposting of official sources to help people navigate and find appropriate information was also considered helpful (12).

Nine development and implementation projects are looking currently at improving information specifically for older people (18, 19, 23, 26, 28, 30, 31, 32, 44, 45). Many of these projects are being carried out by voluntary organisations and are funded through DH Section 64 grants.

Three of these are aiming to develop new and existing websites/web based one stop shops to provide information (18, 26, 30). One of these is the English Dementia Services Development Centre Web Project (18) that will develop a website with information about English Dementia Services Development Centres and provide open access to a database with information about services for people with dementia. Another project is also aimed at people with dementia (26). This is the National Information Resource of Assistive Technologies for People with Dementia which will create a national web-based database of information on assistive technologies, their function, cost and availability. The third is the Elderly Accommodation Council's development of a web-based one stop shop for information about residential care homes (30) in response to the Office of Fair Trading report 'Care homes for older people in the UK' (Office of Fair Trading, 2005).

Two projects are developing open access to databases or registers of information about services (18 and 23). One of these is the English Dementia Services Development Centre Web Project (18) described above. The other is a House Adaptation Advisory Service (HAAS) project (23). This project aims to develop a register of architects, surveyors and occupational therapists with knowledge of the housing needs of disabled and older people, and to whom enquiries about house adaptations and related issues can be addressed. This register would not be available to the public direct, but used by the HAAS helpline staff.

Three projects are aiming to provide information verbally through dedicated helplines or face to face contact (19, 30, 31). One is the Elders Project which is introducing a dedicated helpline for older people with learning disabilities and the staff and families supporting them (19). The Elderly Accommodation Council's one stop shop for information about residential care homes (30) described above will develop a face to face version of the web-based one stop shop so that people who prefer talking one to one can do so. We have no information about the format of the face to face version or how it will be accessed. The Partnerships for Older People Projects (POPPs) (31) aim to develop radical new approaches to the way in which services for older people are delivered locally, including some initiatives that are aiming to improve access to and availability of information. These initiatives include, for example, employing older people as volunteers who pass information by word of mouth, creating a 'network' of information; and employing a team that will provide a high profile, single point of access for older people and staff by operating a telephone service and an outreach facility. These are local initiatives, however, and are not available on a national basis.

One project is aiming to provide personalised advice and information, that is, advice and information that is specific to an individual's own needs, rather than more generic information that is not person specific. This is the SWISH – Smarter Working in Social Care and Health project (32). The project aims to improve older people's and carers' access to appropriate information and services; enrich health and social care databases; and profile local populations by using a self-administered questionnaire (Health Risk Appraisal for Older People - HRAO) to identify health risks and status. The project is being evaluated and is beginning to demonstrate that the HRAO allows the delivery of targeted and personalised advice and information that helps older people to take action to change their health risks.

Few development projects include an evaluation element. The Partnerships for Older People Projects (31) discussed above will be evaluated at the local and national level. The evaluations will consider the effectiveness and consequences of different ways of providing access to information in the local POPPs initiatives. Older people in the SWISH project (32) are taking part in focus groups to explore their perceptions of the value, usability and appropriateness of the information given to them through the health risk questionnaire. In addition, two other government development projects will be evaluated. One is the already established but recently reformatted Over 50s section of the Directgov website (44). The post-launch evaluation will ask people, amongst other things, about the subject areas included, the categories in which information can be found, and the usefulness of the information. Finally, the Link Age Plus pilots (45) have not yet begun but the aim is to pilot models of joined up working across care services. Access by users and professionals to information about services will be part of these pilots. There will be local and national evaluations.

Other projects relevant to older people are also developing methods of providing information about assistive technology (26), community care (28) and residential care (30). These are discussed later under the headings of ‘equipment and assistive technology’ (section 3.2.6), ‘domiciliary care’ (section 3.2.2) and ‘residential care’ (section 3.2.1) respectively.

In some of the projects described above, sub-groups of older people are highlighted. These include people with dementia (18 and 26), older people with learning disabilities (19), older people living at home (28), older people considering a care home (30) and the over 50s (44 and 45).

A further issue that is raised in two projects is the education and training of staff to act as information providers. The Elders project for older people with learning difficulties (19) and the National Information Resource of Assistive Technologies for People with Dementia project (26) both plan to train staff in information giving and helping with service planning.

A voluntary organisation offered the following thoughts on gaps in the access to and provision of information to older people. One group of older people who they believe are poorly catered for in terms of access to information are people with their own property who are not eligible for social services support and therefore do not have access to the same sources of information as those who receive social services support. The respondent considered also that older people from BME groups are hard to reach, but was not sure why they did not access information from the voluntary organisation. She suggested that local BME community groups may be able to provide relevant information themselves (and so there was no need to access information from the voluntary organisation) or that the information provided by the voluntary organisation was not provided in appropriate languages and was therefore not accessible. In terms of formats of information, the respondent considered it important to maintain the option for older people to make enquiries by telephone (particularly important for housebound people) and by letter as many older people continue to write letters and expect a response in the form of a letter as well. More generally, they expressed a concern that people are often treated as a homogenous group, for example the ‘over 65s’, and as a result their individual information needs and problems with accessing information are not considered.

In terms of the types of services about which information is inadequate or hard to find, the respondent from the voluntary organisation suggested the following: health and social care services do not provide information that might be expected, for example, a list of local care homes; where databases give information about local schemes, inclusion is voluntary and therefore many services are missing; and whilst local information centres may be available to local people, they are hard to access if mobility is poor and for people who do not live close by. The respondent considered that many local advice services do not have the in depth knowledge about services and legislation that were necessary, particularly in relation to the third party top up process for people going into a care home or the legalities of property ownership. In general, the subjects that older people want advice and information on are financial rules relating to access to and use of social care services, continuing care and direct payments.

### *3.1.2 People with long term conditions (all ages)*

| | |
|---|---|
| Government-related research projects | 1 |
| Published papers | 0 |
| Government-related development projects | 2 |
| Voluntary organisation interviewed | 1 |

One government research project that will investigate information needs of people with long term conditions is proposed. There are two current development projects that are aiming to improve the provision of information and two others that are proposed. Except for one project aimed at people with epilepsy (20), the development projects described here cover neurological and other long term conditions in general. Given the number of government projects under way and proposed, the literature on information needs was not searched. A voluntary organisation manager was interviewed about gaps in information provision.

As part of the Long-term Conditions Information Strategy (4), government research is planned that will look, amongst other things, at the information that the general public needs about long term conditions, and how it can be made available in an accurate and up-to-date fashion. We do not know when projects related to the Information Strategy will take place, but they will provide evidence on information needs and how these could be met.

Two current development projects that are aiming to improve access to information focus on people with epilepsy (20) and long term neurological conditions in general (29). The Epilepsy Information Network project (20) will provide information about epilepsy through information services in neurology and paediatric outpatient departments, other healthcare settings such as community clinics, health centres and healthy living centres, and residential settings for people with learning disabilities. The aim is to meet the information needs of people with epilepsy and their carers, including providing information to help maximise independence. The Information Access Project to provide information to people with neurological and other long-term conditions (29) aims to support individuals in accessing information directly (no details were available about the ways in which individuals will be supported) and improve access to information by assisting health, social care and other providers to implement evidence-based standards of good practice in information and advice. We are not aware of any plans to evaluate either of these development projects.

One of the two proposed government development projects is the Information Prescription project (37) that aims to develop and evaluate (a) a paper-based information prescription that signposts (that is, points people in the direction of) a broad range of information and (b) a person-centred service that gives localised and personalised information. This project should add to current knowledge about people’s preferences for wide-ranging generic information that they can search themselves, or person-specific information. The other proposed development project (38) aims to produce a specialist neurology branch for the National Electronic Library for Health to enable health and social care professionals to access high quality information and to provide links to a web-based arm of the library through NHS Direct that can be accessed by users and their families. We are not aware of an evaluation of this proposed project.

The voluntary organisation’s views on gaps in information provision relate to both user groups and services. One of the main points made was that although there is a lot of information on the internet, people (particularly older people) cannot access it without the right training, support and equipment. Telephone helplines were considered useful but not as versatile or easy to use as the internet because people sometimes find asking for information difficult when they are not already aware of what information is available. One user group that was noticeable in its absence from accessing information via the voluntary organisation’s information centre was people from BME communities. The information centre had developed an outreach service to take information to BME communities in order to plug that gap. Another large gap was that people do not know where to start looking for information after being given a life changing diagnosis. The respondent also thought that it was very difficult for people who had never had anything to do with social services before to know how to access social services because there was no information about this process. In addition, for people with rare conditions or conditions not supported by the well known and large voluntary organisations, information about emotional support/informal support groups is very hard to find.

### *3.1.3 Physically disabled people*

| | |
|---|---|
| Government-related research projects | 4 |
| Published papers | 0 |
| Government-related development projects | 3 |
| Voluntary organisation interviewed | 0 |

Four government research projects have investigated or are investigating the information needs and accessibility of information for physically disabled people. Three implementation projects have aimed or are aiming to improve access to information. The literature about information needs and accessibility of information for physically disabled people was not searched. No voluntary organisation representing physically disabled groups specifically was approached.

The two recently completed government research projects are an evaluation for DWP of the way in which information is provided on the Disabled People and Carer's section of the Directgov website (9) and a recent investigation for CSCI of the information physically disabled people want about care homes (12). These projects looked at the use of the internet and other forms of communication, and satisfaction with the information available.

For the DWP project, discussions and interviews were held with people between 18 and 65 with sensory or physical disabilities from three areas of England. Results showed that the Directgov website offered very useful information in general for disabled people and respondents believed it was important that there remain a separate section on Directgov for disabled people (9). However, they thought that the current wide ranging content of the site was not immediately apparent; the branding suggests it focuses more on severe disabilities. CSCI's study based on interviews with people with physical or learning difficulties who wanted information about care homes (12) showed that about half the respondents could access the internet but the main sources of information about care homes were friends, relatives, social workers and care managers. A significant minority of adults with physical or learning difficulties, and their relatives, were not satisfied with the ease of obtaining information on care homes (12).

Respondents in the DWP Directgov study (9) considered it acceptable, and even desirable, for the government to provide a wide range of information about everyday life topics, so long as the information was kept up to date and the government was seen to have the appropriate expertise in that area. The project's recommendations include introducing more articles written by disabled people, with more positive case studies providing inspirational information; easier navigation within the site and the ability to customise information; and inclusion of overviews of the different responsibilities of central, local, voluntary and private organisations (9).

Current research projects that may add to this knowledge include the evaluation of individual budget pilots (2) that will, among other things, be looking at the receipt of and use of information to plan support packages, and a project commissioned from the Picker Institute by the DH that is assessing the quality of information about services (predominantly health but also social care services) for specific conditions such as arthritis and lung disease (3).

Three DH Section 64 projects are/have been aiming to increase the accessibility of information about specific services for physically disabled people, namely wheelchairs (17), information for people with spinal injuries (22) and housing adaptations (23). Each project is developing and implementing a new information service, although none is being evaluated for its effectiveness. The Which Powered Wheelchair project (17) aimed to publish a unique interactive guide for consumers choosing a powered wheelchair, scooter or buggy. The Health Information project for people with spinal injuries (22) will develop a ‘unique support service’ to provide people with information on health and independent living, but we have no information about the format or system of the support service. The House Adaptation Advisory Service project (23) has been described above in section 3.1.1 on older people and will aim to develop a register of professionals who can advise on housing and related support.

### *3.1.4 People with learning difficulties*

| | |
|---|---|
| Government-related research projects | 1 |
| Published papers | 0 |
| Government-related development projects | 3 |
| Voluntary organisation interviewed | 0 |

Four government projects related to access to information by people with learning difficulties: one was a research and three were development projects. The literature was not searched for this category of service user. A voluntary organisation representing people with learning difficulties was contacted on six occasions between February and May 2006. There was no information manager able to help and although two helpline staff offered to discuss their views, they did not respond to requests to set up a time for a telephone discussion. As a result, there are no views in this section from a voluntary organisation.

The government research project on access to information for people with learning difficulties is the CSCI project discussed above in section 3.1.3 in relation to people with physical disabilities (12). In the CSCI project (12), the findings were reported jointly with those for physically disabled people; there were no findings reported specifically for people with learning difficulties. These jointly reported findings are that friends, family and care workers are the main sources of information about care homes, but about half the sample use the internet.

Current DH Section 64 projects to improve the accessibility of information for people with learning difficulties are: the Elders Project helpline aimed at older people with learning difficulties (described in section 3.1.1) (19); giving information about pregnancy and access to mainstream maternity services in a booklet (25); and more wide ranging information from the Valuing People Support Team (33). Again, none of these implementation projects is being evaluated. These projects appear to be concentrating on providing information in appropriate formats such as a helpline (19), a booklet (25) and easily accessible material on websites (33). In particular, the Valuing People website www.easyinfo.org provides information about making information more easily accessible and includes guides and tools to enable others to do so. The subgroups of people with learning difficulties whose information access needs are catered for in the initiatives are older people (19) and pregnant women and their partners (25).

### *3.1.5 People with mental health problems*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 3 |
| Government-related development projects | 0 |
| Voluntary organisation interviewed | 1 |

No government research or development projects were identified that related directly to people with mental health problems. Therefore, the recent literature was searched for published articles about information needs and the accessibility of information by people with mental health problems. Four published papers were identified although, on reading the full papers, one was subsequently found to discuss issues relating to all disabled parents, not only those with mental health problems. Three papers are therefore presented here that consider, at least in part, access to information about social care services for people with mental health problems. In addition, a voluntary organisation gave their views on possible gaps in information provision.

Silveria and Allebeck's (2001) paper on anxiety and depression in older Somali men in London gives no specific details about information requirements but does suggest that older people, including those with mental health problems, are less inclined to ask for help. In addition, a Joseph Rowntree Foundation (JRF) (2005) report on direct payments for mental health service users stresses the importance of providing information to people before, for example, they are discharged from hospital or to

BME communities through outreach work. The reason for this is that it is important to ensure that information is not only accessible but also is targeted at particular groups of people who might otherwise be excluded from mainstream information services or reticent in asking for information.

In their questionnaire survey of mental health problems and social support among homeless mothers and children who have been victims of violence, Vostanis *et al*. (2001) report that 30.2 per cent of mothers wanted more advice and information. Unfortunately, the paper does not give details about the types or topics of information wanted, and the main questionnaire results relate to general health and other characteristics of the mothers and children, rather than to information needs. However, the JRF report (2005) on direct payments suggests that information provided for people with mental health problems should be straight forward, using real life examples to demonstrate how direct payments can be used. In addition, the report encourages appropriate training for staff in relation to direct payments as there was evidence that both users and professionals were confused about the different thresholds of eligibility for access to social care assessments and access to social care services.

The voluntary organisation representing people with mental health problems suggested that in general people are not sure where to go for information. Not enough information is available in GP surgeries or other centres where people can easily see and pick it up whilst they are there. Internet access for people with mental health problems varies; the voluntary organisation is planning to create a drop-in centre where people can go to use the internet. One service that many people contact the organisation about is affordable counselling without a waiting list. This is an issue for people who have not been referred through the NHS and cannot afford private counselling. For carers of people with mental health problems, information about respite services, residential care and day centres was reported to be hard to find.

### *3.1.6 BME groups*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 1 |
| Government-related development projects | 0 |
| Voluntary organisation interviewed | 0 |

No government projects were identified that were specifically either investigating information needs and access to information or developing methods to improve access to information about social care services for BME communities. The literature search identified only one relevant article. As ‘BME communities’ are diverse groups of people with a range of information access needs, it was not appropriate to contact a single voluntary organisation for an interview. However, each voluntary organisation contacted as representative of the other user groups was asked also about information provision to BME groups. These views have been highlighted in the relevant sections.

The published literature gives little evidence on information needs and access to information for BME groups. No articles with a primary aim of investigating information needs and access were identified. The one relevant article that was identified has been discussed already in the section on people with mental health problems. This article is about implementing direct payments in mental health, but includes a recommendation that information on direct payments is targeted at specific groups, including BME communities (Joseph Rowntree Foundation, 2005). As explained above, the reason for this targeting is to ensure that information is made accessible to groups of people who might otherwise be excluded or reticent in asking for information.

BME communities are a very under-represented group in both the literature on information needs and in government research and development projects. No projects or published papers were found on the nature of barriers to BME communities in accessing information about social care services or how these might be addressed.

### *3.1.7 People with HIV/AIDS*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 2 |
| Government-related development projects | 0 |
| Voluntary organisation interviewed | 0 |

No government research or development projects were identified that focused on information access issues for people with HIV or AIDS. A literature search identified two papers. Five attempts were made to arrange a telephone discussion with a voluntary organisation but no one was available to help within the timeframe of the study.

Both published papers considered mainly information about health care but did comment briefly on information about social care services. Thorne *et al*. (2000) studied issues related to the disclosure by parents with HIV/AIDS of their diagnosis to their children. One of these issues was the planning of future support. The paper raised the question of where families could go to access help and support with planning their children's long term social care. Anderson and Doyal (2004) explored a range of issues about the lives of African women with HIV living in London.

Relevant findings show that hospitals and clinics were considered safe environments and major sources of information about health and social care.

### *3.1.8 People with drug or alcohol problems*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 1 |
| Government-related development projects | 0 |
| Voluntary organisation interviewed | 1 |

No government research or development projects were identified that focused on access to information about social care services for people with drug or alcohol problems. A search of the literature identified one paper that considered access to information for drug misusers. A voluntary organisation representing drug abusers gave their views about information needs and access to information on social care services.

The published paper that considered access to information for drug abusers (Mitchell and McCarthy, 2001) described research that involved following up prisoners who had left two London prisons. The paper concentrated on use of services, but observed also that voluntary sector providers were often unable to gain access to prisoners inside prison to give counselling and advice. Neither prison had a system for providing those who had been through detoxification with information on release about drug counselling in their locality. Both these observations suggest prisoners are lacking access to appropriate information at appropriate times.

The information manager at the voluntary organisation representing drug abusers gave a similar view: prison leavers do not know where to go or how to get information. She expressed a concern that a lot of information tends to be medical or aimed at academic audiences and as such is not accessible to the public or drug users. Many drug users have a low level of education and thus find using the internet problematic. When training courses in internet use are provided, people often drop out. Training courses and internet usage are particularly difficult for those with more chaotic lifestyles and people with learning difficulties. There is a high demand for information provided in leaflet form and in languages other than English.

In terms of access to information about services, drug users find it hard to get information about who will prescribe methadone and the location of needle exchanges. It is difficult to obtain information about residential care, in particular detailed information such as homes that take, for example, pets and are also wheelchair accessible. Information is also hard to find about services that are available for free or services for which grants are available.

One major concern from this voluntary organisation was that advice and information helplines are sometimes forced to close due to a lack of funding or when funding is made available only to develop new services, not to maintain or enhance existing services.  This can leave a large gap in information accessibility.

### *3.1.9 People with sensory impairments*

| | |
|---|---|
| Government-related research projects | 1 |
| Published papers | 4 |
| Government-related development projects | 2 |
| Voluntary organisation interviewed | 1 |

One government research project that investigated the accessibility of information for people with sensory impairments and two Section 64 funded development projects were identified.  The literature on information and people with sensory impairments was also searched.  (Only one government project had been identified at the time of the literature search; details of the other two projects were provided at a later date. Had they been provided earlier in the study, the literature would not have been searched.)  Four papers were identified: three presented the results of research on the information needs of people with visual impairments and one on the information needs of parents with deaf children.  In addition, a voluntary organisation for people with visual impairments provided views on gaps in the availability of information.  Two different voluntary organisations representing deaf or hearing impaired people were approached for their views but no one was able to help within the time limits of the study.

The government research project that investigated the accessibility of information for people with sensory impairments was an evaluation for DWP of the way in which information is provided on the Disabled People and Carer's section of the Directgov website (9) and has been described previously in section 3.1.3 about information for physically disabled people.  Discussions and interviews were held with people between 18 and 65 with sensory or physical disabilities from three areas of England to ascertain their views of the information provided.  Specific issues for people with sensory impairments were not reported separately from those for people with physical impairments.  Results showed that the Directgov website offered very useful information in general for disabled people and respondents believed it was important that there remains a separate section on Directgov for disabled people.  However, they thought that the current wide ranging content of the site was not immediately apparent as the branding suggests it focuses more on severe disabilities.

The articles identified from the literature search provided more detail on the information needs and accessibility of information for people with visual impairments and parents of children with hearing impairments.  One of the areas about which there is a lack of information for people with visual impairment is equipment. Beverley *et al*. (2004) found, through a systematic review of the health information needs of visually impaired people, that they wanted more information about visual aids and mobility support. Similarly, Percival and Hanson (2005) reported the results of a questionnaire survey of visually impaired older people. They found that a lack of information about equipment that would enable visually impaired older people to take part in everyday activities was affecting their lives and independent living.

Providing information in the right format and the right place is also important. Suggestions from the systematic review (Beverley *et al*., 2004) include producing information in large print, Braille, computer disks, talking newspapers, the internet, TV, and via verbal communication. Braille, it is reported, is popular with the people who use it, but only a small number of visually impaired people read Braille. The Thomas Pocklington Trust (2003) reported in more detail on the same study as Percival and Hanson (2005). The Thomas Pocklington Trust paper reported that respondents in the older people's survey would like to see resource centres that could act as one-stop shops for information, advice and support. The survey respondents felt that this could reduce the current maze of services and systems. Respondents suggested that these resource centres should provide professionally staffed services for people with sight loss under one roof; be in a central location with meeting rooms and facilities for groups; and provide, for example, advice, advocacy and equipment loans. Although some centres exist already, none provide the whole range of services under one roof.

Overall, there was a lack of information generally about social care services, and this was particularly apparent for minority ethnic groups with visual impairments (Percival and Hanson, 2005). Most information on health and social care that was received by people with sensory impairments came from GPs, district nurses, hospitals and home care staff (Beverley *et al*., 2004). Beverley *et al*. (2004) identified as the main gaps in information provision for visually impaired people the lack of a co-ordinated approach between health care, social care and other providers of information; inadequate use of library and information services; and a need to recognise the heterogeneity of visually impaired people.

In relation to hearing impairments, Robinshaw and Evans (2003) present findings from a study about parents' experiences of the information made available to them at the time of diagnosis of their child's deafness and in the early years. They give details of the information parents would ideally like to have and the means they have found useful for accessing information. Data were collected from focus groups with parents of deaf children. Although this paper focuses on services for deaf children, it gives useful insights into parents' views on accessing information in their roles as carers. The preferred ways of imparting and accessing information were information packs, wall displays, comprehensive and regularly updated directories and lists of national and international contacts (email, postal, and web addresses). Primary sources of information were: professionally supported parent groups; parent-specialist consultations; group tuition sessions; and infant peer group activities. The authors also report that for every comment about the lack of information from statutory services there was one emphasising the importance of informal parent support groups. There was also frustration that neither local professionals nor national voluntary organisations had directed parents to alternative or additional service provision in the private or voluntary sectors.

One of the two development projects is being undertaken by SENSE, the National Deafblind and Rubella Association. It is a development project funded from a DH Section 64 grant that aims to increase the availability of information to deafblind people by developing accessible technology, including a catalogue and website on aids and equipment (27). We do not have information about the format or methods this project is using to make this information accessible and we do not know of an evaluation of the project.

The other government development project is another Section 64 funded project aimed at visually impaired people (21). Action for Blind People is aiming to establish information and support services for visually impaired people in eye clinics. From the information we have, it is not clear what or how the information will be provided, but the aims of the project are to identify gaps in current information and support services, and to develop pathways for liaison between health care, statutory services and voluntary organisations in the provision of those services. Again, it is not clear whether any evaluation of this project is planned.

The information provided by the voluntary organisation representing visually impaired people reported that BME groups often did not access information. They were not sure why this was the case but suggested that there may be a vicious circle in that information was not provided in appropriate formats and languages, therefore the BME community did not make contact because they knew the information was not appropriate for them, and as a result information was not developed in appropriate formats because no one ever asked for it. BME groups may also be reluctant to ask for help or to contact voluntary organisations that can be perceived as white and middle class. There are few visual impairment support groups aimed specifically at BME communities. Where there are, they are for Asian communities; Chinese communities in particular are not well catered for. For communities where literacy levels are not high, information needs to be provided verbally, for example on tapes. Braille is very popular with the small percentage of people who read it. Information on the internet can be accessible but needs to be available through speech output or screen enlargements. People with visual impairments and hearing impairments are another group who are neglected when it comes to information provision. In terms of information about services, information on day centres is perceived by the voluntary organisation to be less comprehensive than it could be.

### *3.1.10 Carers and informal providers*

| | |
|---|---|
| Government-related research projects | 1 |
| Published papers | 1 |
| Government-related development projects | 1 |
| Voluntary organisation interviewed | 1 |

One recent government project has investigated the information needs of carers and one government development project is underway. (Another government development project is proposed but not yet in the planning stages.) The literature on carers and information was not searched because these three government projects are already adding to current knowledge about the accessibility of information for carers. However, one article about carers was identified in the literature search for papers about access to information on respite care. Relevant details from this article have been included here. A voluntary organisation that provides information for carers also gave views about information needs and gaps.

The government research project that was identified is a DWP in-house review of carers' information needs (8). The findings suggest that the types of carers that find most difficulty in accessing information are those from BME communities, young carers, carers in rural areas, those caring for disabled children, people with a mental health illness, learning difficulty or physical disability. Personalised advice, that is, information that is tailored to the individual's needs, was suggested in this study as a way of improving information provision, as were, amongst other things, one stop shops and information packs.

The article identified in the literature search on respite care, and which included information for carers, was by Evans *et al*. (2001). The article reported findings from a literature review, followed by a questionnaire survey of parent carers in Wiltshire about their needs. The literature review revealed a lack of information about support available for carers as well as a lack of services providing information for this group of carers. Results from the questionnaire showed that the lack of information about service availability was a major factor in the inequitable provision of support services for carers. Key information points for carers were special schools, special education units, other carers and hospitals. The paper recommended the development of a comprehensive service directory giving information for carers in Wiltshire. The generalisability of these findings to carers in localities outside Wiltshire is not clear.

The current development project is SWISH (Smarter Working in Health and Social Care) (32) which is aimed at older people and carers. This project is using an 'expert system' called the Health Risk Appraisal for Older People which has been tested in a pilot in three European countries. The system includes a questionnaire to identify risk factors; the system takes the results of the questionnaire and produces specific personalised advice on how to change health risk behaviours. It thus delivers targeted and personalised advice and information. The development and use of this questionnaire is being evaluated. For example, older people are taking part in focus groups to explore their perceptions of the value, usability and appropriateness of the information given to them through HRAO.

The DH has also made a commitment in the White Paper '*Our Health, Our Care, Our Say*' (Department of Health, 2005) to provide an information service/helpline for carers (34) that will offer a wide range of information, advice and other points of contact from legal entitlements to contact numbers for support groups to advice on benefits.

Views from the voluntary organisation about the accessibility and availability of information to carers are as follows. Many carers do not know where to start to look for information or how to make initial contacts; carers often contact the voluntary organisation for information before they realise that it is social services they need. Despite information often being available, carers don't know where it is or how to find it. A lot of information is available over the internet but there are carers, especially older carers, who still want paper copies. Telephone helplines are very important to older carers, particularly those who have problems with mobility that make it difficult to go out and those carers who do not have the time to go out and visit information centres. Others want information in large print. The respondent noted that non-English speaking people do not call English speaking helplines even where language line interpreters are available. In terms of needs for information about certain types of services, carers are confused about residential care and charging policies and they also need support and information about how to set up a direct payments package.

## 3.2 Information needs and accessibility about types of social care services

The following section gives details of government research or development projects and, where appropriate, literature about the accessibility of information about different types of social care services. No discussions were carried out with voluntary organisations specifically on access to information about different types of social care services as voluntary organisations are based primarily around services users, not types of services.

### *3.2.1 Residential care*

| | |
|---|---|
| Government-related research projects | 1 |
| Published papers | 0 |
| Government-related development projects | 1 |

One recent government research project investigated the methods by which people accessed information about care homes (12) and a current Section 64 project is developing a one stop shop for advice on care homes (30). The literature on residential care was not searched for information on care homes, but the search for literature on domiciliary care did identify one article about residential care. Details of that article are therefore included here.

The government research project that investigated the methods by which people accessed information about care homes (12) found that a sizeable minority of elderly or disabled respondents thought it was difficult to source information on care homes or were unsure how easy sourcing such information would be. The main sources of information on care homes were friends, relatives, social workers and care managers. Whilst half the respondents were able to use the internet, most care users consulted welcomed large print, 'easy read' and video formats. This project has been described also in the previous sections on older people (section 3.1.1), physically disabled people (section 3.1.3) and people with learning difficulties (section 3.1.4).

The published article by Thompson and Wright (2000) investigated, through interviews with spouses of people in residential care, the liable relatives rule that sets out when a spouse must pay a contribution to residential or nursing home care. Themes arising from the interviews with spouses were that there was a lack of information about spouses' liabilities for payments and, where information was available, it was difficult to understand. Spouses were uncertain about what was a reasonable contribution to pay and were unaware that negotiations with the councils about payments were possible. More generally, interviewees were unaware that the rules for payment changed when resident status changed from temporary to permanent, and there was confusion between the relatives rule and the third party top up rule (the former being a means-tested contribution to council funding and the latter a voluntary top up to permit residence in a more expensive care home than council funding allows).

The government implementation project is a Section 64 project to develop a one stop shop for care home advice (30). It has arisen from the Office of Fair Trading's (Office of Fair Trading, 2005) report on care homes for older people in the UK. There will be a web-based version of the one stop shop and a face to face version so that people who prefer talking one to one can do so. We do not have any information about the format or location of the face to face version. The one stop shop will provide links to care home inspection reports but also give softer information such as details of activities that take place in the homes.

### *3.2.2 Domiciliary care*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 3 |
| Government-related development projects | 1 |

No government projects were investigating the accessibility of information about domiciliary care. One government development project (a Section 64 grant) is aiming to increase the accessibility of information about community care charges. The literature search revealed four articles about information and domiciliary care services, although one article was subsequently re-classified as being about residential care and has been described in section 3.2.1.

One of the research articles (Thomas Pocklington Trust, 2003) has been discussed previously in section 3.1.9 on sensory impairment. The paper presented results from a questionnaire to find out the views of visually impaired older people on social care and inclusion. Although two of the issues raised were access to information and people's support needs within the home care environment, the findings do not offer any insights into information needs about home care services. The findings showed more generally that there was a lack of information about social care services and that information offered by hospital eye clinics about community support services was limited.

Holmes and McMullen (2003) reported, on behalf of the Coalition on Charging, on the impact of the Fairer Charging policy on disabled and older people and their carers in England. The Coalition on Charging is an alliance of 200 national and local organisations that are opposed to charging for essential non-residential social services. The report presented findings from a survey of the impact on the real lives of older and disabled service users of 2002 national guidance 'Fairer charging for home care and other non-residential social services'. Findings indicate that a majority of users and carers find it difficult to get the information they need about local authorities' charging policies. Charging for essential services continues to have a negative impact on people's finances and lifestyles. Whilst a majority of respondents found that charging policies did not act as a barrier to gaining employment, some were deterred from seeking employment because they *perceived* it would affect their care package. Recommendations include that, at the time of the charge assessment, councils must ensure that 'comprehensive' benefit advice is available and those who are to carry out benefit assessments must be trained correctly on welfare benefit issues.

The other article is a report by a group called Health and Older People (HOPe) (Help the Aged, 2000). The group was supported by Help the Aged. It was an independent group of 15 people who were retired and had diverse national and local experiences. They did not purport to be representative of organisations or areas but were confident their report reflected the views and experiences of older people in England. The report gives findings from ‘discussions and reflections arising from the group’s involvements in formal consultations and their experiences of older people’s everyday realities’. The report does not focus solely on domiciliary care; it covers wider issues (that include information about and the provision of social care services), that the group believed needed to be addressed in order to make progress on the future well-being of older people. A small number of findings relate to information needs. The report suggests that people need the right information at the right time and in a range of formats (written, spoken and in various languages). It suggests also that information alone is not sufficient; information needs to be backed up with the opportunity to talk to an informed person.

The government development project (a Section 64 grant) aiming to increase the accessibility of information about community care charges is being undertaken by the Disability Alliance (28). This project has been set up to address the fear felt by many older and disabled people about the cost of community services. This fear, combined with a lack of understandable information about how the charging system works, can act as a barrier to access to services. The project aims to produce a user-friendly guide which will provide a summary of the legal position on charging for community care services and will also explain Direct Payments and the role of the Independent Living Fund. No details have been provided about the format or distribution of the user-friendly guide, other than it will be used by disabled and older people and their carers and also by local authority staff and advisers in local agencies.

### *3.2.3 Short breaks and respite care*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 0 |
| Government-related development projects | 0 |

No government projects were identified that were either investigating or trying to improve access to information about short breaks and respite care. The literature was searched but this identified only one paper. Although classified as both information and respite care in the databases searched, the paper in fact reported on a literature review and questionnaire completed by parents about the needs of parent carers of disabled children in Wiltshire (Evans *et al*., 2001). There is no mention of information about respite care. Details of this paper have been included in section 3.1.10 on carers.

### *3.2.4 Day centres and day time activities*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 0 |
| Government-related development projects | 0 |

No government projects were identified that were either investigating or trying to improve access to information about day centres or day time activities. The literature was searched but this did not identify any papers either. We therefore have no recent information about needs for, or the accessibility and availability of information about day centres or day time activities.

### *3.2.5 Intermediate care*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 2 |
| Government-related development projects | 0 |

Intermediate care is defined as care for patients in transition from hospital in-patient care to care at home. It can be seen as a stepping-stone allowing a patient to make the transition within a supported environment to independence. Intermediate care services may be provided at home, in a community hospital, a purpose built unit or residential care home.

There were no government research or development projects identified that focused on information about intermediate care. A literature search identified three articles. Two of these research articles investigated information needs in relation to stroke care (Robinson *et al*., 2005, Mold *et al*., 2003). The other article (Burrows *et al.*, 2000) looked at the growth in use of the internet to find information and was not relevant to information about intermediate care in particular. It has been included instead in the section on equipment.

One of the articles was a literature review (Mold *et al*., 2003). The findings showed a general lack of satisfaction with the provision, quality and content of information materials about stroke care, including intermediate care. In particular, few studies had investigated whether information provided was appropriate to people with different levels of literacy, education or visual ability. A key point for people who have had a stroke is that their cognitive ability or vision may be impaired. Informal support networks were the main source of information after stroke but the findings showed that certain groups were poorly provided for; for example, foreign language literature and interpreting services were inadequate (Mold *et al*., 2003).

The paper by Robinson *et al*. (2005) described the development of a course for carers of first time stroke victims. The main factor discussed in relation to information was the recognition that people wanted to have information in response to certain issues, rather than to acquire knowledge as an end in itself. The paper did not report on an evaluation of the course or the usefulness of the information that it provided.

### *3.2.6 Equipment and assistive technology*

| | |
|---|---|
| Government-related research projects | 0 |
| Published papers | 1 |
| Government-related development projects | 4 |

There were no government research projects to investigate access to information about equipment and assistive technology. One recent and three current government projects aim to improve the accessibility of information about equipment and assistive technology. The literature was searched for articles that investigated information needs and access to information. No relevant articles were identified. An article that was mainly about carers was identified and has been included in the section on carers instead. One article was identified in the search for literature on intermediate care but gave examples of ways in which information about equipment can be accessed, so has been included here.

This paper by Burrows *et al*. (2000) reported on the implications for social policy of the growth of internet use. One section gave an example of people using internet news groups for finding out information. The example was of a UK newsgroup used by disabled people. As well as news and general social contact, people have used the newsgroup to find out information about equipment, others' opinions of equipment and where to buy it. Internet news and chat groups are therefore other channels for accessing information.

The government-related projects to improve access to information about equipment and assistive technology include information about powered wheelchairs and scooters (17), housing adaptations (23), assistive technology for people with dementia (26), and low level equipment needs (46).

Personalised information (that is, information relevant specifically to the person enquiring) features in two of these projects. The DH and Disabled Living Foundation (DLF) have developed a web-based, self-assessment tool to enable people to assess their low level equipment needs and identify appropriate products from a large database of different types of equipment (46). The DLF is further developing and evaluating this product. Also, a Section 64 grant funded the development of an interactive guide for consumers choosing a powered wheelchair, scooter or buggy (17). We do not know of any evaluation of this guide. It is not clear whether the information provided in each of these projects is aimed mainly at private purchasers or also at people who might be eligible for equipment through social services or the NHS.  The DLF website gives details of the suppliers of equipment, which implies the information is for private purchasers, but also encourages healthcare professionals to access information on equipment and its suppliers.

The other projects (23 and 26) have been described in earlier sections on physically disabled (section 3.1.3) and older people (section 3.1.1) respectively.  Each is developing a directory or web-pages of information, but neither is personalised or interactive.

### *3.2.7 Advice and information centres*

| | |
|---|---|
| Government-related research projects | 1 |
| Published papers | 0 |
| Government-related development projects | 1 |

One government research project investigated the use of online information centres about social care and a Section 64 grant is being used to fund the development of a website which will include details about information centres for people with dementia. The literature was not searched for papers about information and advice centres.

The government research project was about the use of UK Online Centres (6) and has been described earlier in section 3.1.1 on older people.  The study reported in 2005 on the potential of UK Online Centres to stimulate increased use and support people in accessing government e-services, which include government websites such as Directgov that provides, amongst other things, information about social care services.  About a third of people asked said they would, with appropriate support and training, use online services either at a local library, online centre or elsewhere. Over 80 per cent of people using UK online centres would use a one-stop government website if they received training in how to do so.  However, we do not know how many of these 80 per cent would use such a site to access information specifically about social care services.  Of people who were newly introduced to e-government services, half said they would use them again because, amongst other things, they found information easy to access and relevant.

The other government project is an ongoing development project aiming to produce a website with information about English Dementia Services Development Centres (18). The website will also provide open access to a database with information about services for people with dementia.  We do not know of any evaluation of this project.

## 3.3 Information needs and accessibility for other groups and services

| | |
|---|---|
| Published papers | 1 |
| Government-related development projects | 6 |

A small number of other government projects considered information for/about specific groups or services: direct payments (11 and 28); legal rights and entitlements (14 and 28); disabled parents (10, 14, 25); and vulnerable people (41). Although the literature was not searched for articles about the information needs of other user groups or services, one article about disabled parents' needs that was identified in the searches for articles on the information needs of people with mental health problems and people with sensory impairments. It is included here.

The National Centre for Independent Living reported in 2005 on research into the implementation of Intensive Support Schemes for direct payments (11). Types of support schemes included Independent Living Trusts, Third Party Payments, Brokering and User-controlled Personal Assistance Agencies. One of the reported problems with implementing Intensive Support Schemes was a lack of easily accessible information for advisors or individuals contemplating direct payments. The provision of clear, accessible guidance and practical resources to help people understand the role of Intensive Support Schemes for direct payments was recommended. The other government development project relevant to direct payments is a Section 64 grant discussed previously in the section on domiciliary care; in it, Disability Alliance is developing a user-friendly guide to direct payments as part of its Understanding Community Care Charges project (28).

Two government projects aim to improve access to information about legal rights and entitlements relating to social care services. Both are Section 64 grants. The Disabled Parents Network aimed to research, produce, launch and distribute a handbook that would inform disabled parents of their legal rights and entitlement to social and health services (14) (the project finished in 2005). The Understanding Community Care Charges project mentioned above will, in its user-friendly guide to charges, include a summary of the legal position on charging for community care services for disabled people in general (28).

Three government projects relate specifically to disabled parents. One of these projects is a knowledge review by SCIE of support for disabled parents. It is ongoing and it aims to investigate the views and need for choice, independence and support of disabled parents (10). Investigations of information needs and accessibility are not mentioned explicitly in the project summary but are a pre-requisite for making choices in order to maintain independence. Two Section 64 projects are developing handbooks on (a) the rights and entitlements of disabled parents as described above (14) and (b) information that parents with learning difficulties need to help them make choices and use mainstream services (25). This project has been described earlier in the section on people with learning difficulties.

In addition, the searches for articles on the information needs of people with mental health problems and people with sensory impairments each identified a report of a consultation by the Disabled Parents Network (Wates, 2003). The report included the views of all disabled parents and so is more appropriately included in this section. This report may be part of the Section 64 project to develop a handbook on the rights and entitlements of disabled parents described above (14). It is based on questionnaires, interviews and focus groups with 150 disabled parents and was carried out in preparation for a disabled parents' handbook. The report looks at both information and support needs but does not always separate the two. Findings suggest that disabled parents report difficulty in getting information at times of crisis and when needs change suddenly, and that poor information is an issue throughout a parenting career. Whilst voluntary organisations are popular sources of information, the most popular format for providing information was a loose-leaf handbook; the internet was the second most popular format. The need for constantly updated information was recognised as a challenge.

Finally, ODPM (now DCLG) has developed and put on the internet a directory of Supporting People services. Supporting People offers vulnerable people housing-related support that complements existing services. Services can be long or short term and include accessing a community service alarm, a home visit for a short period each week or an on-site full-time support worker for a longer period of time (41). The project team is investigating how the directory can be improved using web feedback and regional preview events. Work is also ongoing to improve the usability of the software, the quality of data, and to keep the directory details up to date.

## 3.4 Other government projects not aimed at specific groups or services

| | |
|---|---|
| Government-related research projects | 3 |
| Government-related development projects | 11 |

The remaining government projects did not specify individual user groups or services but aimed to cover all users of social care services. Three government research projects have investigated or are investigating information needs and accessibility. Eleven are aiming to improve the accessibility of information through new developments: four of these are recently completed or ongoing DH Section 64 projects; four are planned by the DH; two are under way in ODPM (now DCLG); and one has been completed by CSCI.

The three research projects investigating information needs and accessibility are: a recent report by NHS Direct New Media on accessible formats of information provision for the patient information bank (1); the ongoing evaluation of individual budget pilot sites (2); and phase one of an ongoing study by the Office for Disability Issues on information needs of disabled people (5).

NHS Direct New Media is developing a ‘Patient Information Bank’ on behalf of the DH (1). This is a bank of quality assured, evidence-based health information leaflets and fact-sheets that all health professionals in the NHS could use for and with their patients. Although health information dominated, social care information is not excluded. The objectives of the accessible formats project were to (a) gain expert and lay input into the best way to provide accessible information through a consensus development panel, and (b) to undertake a brief literature review to explore relevant accessibility issues. Findings from the expert and lay panel include: people who have sensory impairments, learning disabilities, dexterity problems or literacy problems are most likely to have difficulty in accessing information in standard formats; and people using non-English languages need translation and interpretation services, and the main languages involved may change over time. Findings from the literature review suggest that the main accessibility barriers to effectively using health information are related to socio-economic factors, sensory impairments, learning difficulties, a lack of basic literacy skills and an inability to read English. The report suggests that these may be overcome in part by increasing internet access; paying attention to font size, colour, layout and plain English; and ensuring appropriate and effective translations.

The aims of the evaluation of individual budget pilot sites (2) include assessing the effectiveness of different models of budgets and the experiences of different user groups. Individual budgets aim to offer people entitled to social care and/or other services greater transparency, choice and control over how their needs are met and enable them to access a wider range of services than currently possible. The groups included in the evaluation are older people (including those with dementia), physically disabled and sensory impaired people, and people with learning disabilities, mental health problems and long term health conditions. A sample of individual budget holders will be interviewed two months after being given an individual budget. As part of this interview, individuals will be asked about the information they wanted to access and were able to obtain to help in planning their support packages.

Phase one of the ongoing study by the Office for Disability Issues on information needs of disabled people (5) has been completed. The project has included a literature review to determine what is known from government and academic research on disabled people’s experiences and information needs; and a mapping of services supplied to disabled people by central and local government and the role of the voluntary sector. Results from the literature review suggest, amongst other things, that: there is a lack of, or misleading, information; information is fragmented where individuals have to access different forms of support and cross-departmental information is not joined up; and intermediaries such as the voluntary sector and families play an important role.  Results of the mapping of information services will show which department manages each government provided service, what the service is about, and the channels through which information is provided, for example, online, helplines, or leaflets.

Of the 11 government projects that are aiming to improve the accessibility of information through new developments, three are recently completed and one is an ongoing DH Section 64 project.

One of the completed projects included an evaluation element (13).  This project by DIAL aimed to support local DIAL advice centres to achieve the new DIAL UK Quality Standards.  It aimed to provide practical targeted development support to DIALs to assist them to provide high quality advice and information to the 250,000 disabled people using their services each year.  The evaluation consisted of an auditing process to accredit the quality of their services.  We have no information about the results of the audit.

The Disability Law Service has also recently completed a project (15) that aimed to increase the capacity of the Disability Law Service to assist disabled adults and children seeking advice and support in accessing services from their local health authority and/or social services and to offer support to other organisations providing information and advice for disabled people.  We do not know of an evaluation of this project.

The Website Information project (16) by the Disability Alliance aimed to provide a unique, on-line, expert resource on social security and other benefits and services for disabled people.  It aimed to help improve the quality of the service provided by local advice agencies to their disabled customers and to promote independence by providing disabled people with access to information so that they can make informed choices.  We do not know of an evaluation of this project.

One Section 64 project is still ongoing.  It involves the development of a one-stop electronic information service to connect people in need to available help and resources (24).  The aim of this project by StartHere is to build a unique fully integrated database that connects people to statutory and voluntary sources of help and support, both nationally and locally.  We do not have any further details of this project or know of any planned evaluation.

Four projects are currently proposed by the DH or are in the planning stages.

The Information Accreditation Scheme (36) is due to be implemented by the end of 2007.  This implementation project aims to improve the quality of information on health and social care by accrediting information providers who reach minimum standards.  Accredited providers will display a visible quality ‘kite mark’ that is recognisable to users.  Currently in the planning stage is a Health Search Engine (35) that will aid quality assurance by linking to the information accreditation scheme described above.  Through signposting, it will assist people in finding good quality information that is relevant to them.

Due to begin in mid-2006, the Community Information Bank project (39) aims to develop a database(s) that will be used to provide locally based information, for example about support groups or care homes, to helplines and other information providers.  One of the aims is to work with PCTs, local authorities or others to investigate how an integrated database about services can be developed and kept up to date.  Methods of keeping the database up-to-date will be tested.  The project is linked with the Information Prescription project (37); it will be used to supply information for the information prescriptions.  The project supports recommendations for community navigators in *Better Information, Better Choice, Better Health* and *Our Health, Our Care, Our Say* (Department of Health, 2004, 2005)

Proposed in *Our Health, Our Care, Our Say,* (Department of Health, 2005) but not yet in the planning stages is the Social Care Link project (40).  The suggestion is that every local authority should have a detailed directory of information about social care services, integrated with health.

Two development projects are being undertaken in ODPM (now DCLG).  In one, templates for developing web-based fact sheets are being sent to all councils (42). Included with the 221 fact sheet templates (covering mainly social services information but also environmental information) will be a resource pack and a handbook for staff on how to write, code and monitor the fact sheets together with all the marketing communications artwork for councils to use if they wish to advertise the fact sheets in their area.  The project originated with Oldham Council which was chosen as a marketing pilot by the E-Citizen project.  ODPM (now DCLG) funds the E-Citizen project which conducts market research and tests marketing communication campaigns in order to raise awareness and drive take-up of local authority e-channels.

ODPM (now DCLG) is also undertaking a project to connect local authority information to Directgov (43).  This programme aims to improve accessibility to public services via the internet by ‘deep linking’ from Directgov to a local authority service or interaction page.  ‘Deep linking’ means that internet users will be able to click on a web link on Directgov and be directed not just to a local authority home page, but straight to the relevant section.  This saves people from having to search for information twice – once on Directgov and again on their local authority’s website. Users only have to learn how to navigate one website.

The final government-related development project has been undertaken recently by CSCI.  CSCI has published a guide called ‘Social Care – Choosing The Right Service

For You' (47).  This new guide gives people advice and information about choosing social care.  The guide was designed to fill the gap in good quality information available to people looking for or using care services.  It encourages people to ask the right questions when looking for care and to say no if they are unhappy with what is being offered.  Copies of the guide will be sent to every council in England; it will also be available on CSCI's website and in alternative formats for disabled people and different languages for people who do not read English.  An evaluation of the guide will include analysis of the take up of different formats.

# 4. Summary of results

Part one of this section summarises the information needs and accessibility issues identified from government research projects and recent literature, and shows how government development projects aim to address some of these issues. Part two highlights the user groups and social care service types for which we have no research evidence about information needs or the accessibility of information.

## 4.1. Summary of research evidence on information needs and the accessibility of information, and the extent to which these are being met by current or planned government-related development projects

This section summarises the information needs and accessibility issues identified from government research projects and recent literature, and shows how government development projects are addressing, or aiming to address, these issues. The evidence for each of the information needs is presented, followed by details of the government development projects that are addressing these needs. Needs that have been identified but are not being addressed are also highlighted.

The information needs and accessibility issues identified from government research projects and recent literature are that people want information that is:

- in an appropriate format for them;
- easy to find without having to search numerous sources;
- personalised;
- targeted and timely;
- of good quality; and
- provided by staff who are knowledgeable.

In addition, this section highlights the research evidence on the types of services about which information is hard to find and development projects that address these needs.

### *4.1.1 People want information in appropriate formats*

The results of this review have shown that people want information provided in the right formats for them. User groups that have been highlighted as having specific needs relating to the format of information are older people, visually impaired people, people from BME communities and people with chaotic lifestyles.

- For older people, traditional formats such as written letters are still popular. Other suitable formats include large print, easy read formats and video presentations (12).

- For visually impaired people, a wide range of formats has been suggested: Braille, computer disks, talking newspapers, the internet, television and verbal media are all important (Beverley *et al*., 2004). Some of these formats, for example the internet, may need supportive measures such as screen enlargements or speech output to ensure they are fully accessible to visually impaired people. There has been little research into the appropriate formats of information for people who have dual impairments, for example, visual impairments as a result of, or combined with, a medical condition such as stroke (Mold *et al*., 2003). There is a danger for these people that while information is provided about some aspects of their support needs, for example services for post-stroke support, it is not always accessible because of visual or cognitive impairments.

- The NHS Direct New Media report (1) on accessible formats suggests some access barriers for BME communities may be overcome by ensuring appropriate and effective translations. We do not know how ‘appropriate’ and ‘effective’ have been defined in the report. Many of the voluntary organisations interviewed also raised the point that people from BME groups actually need to know that information is available in languages other than English. Written information may not always be appropriate as literacy levels in minority ethnic groups can be poor. Verbally transmitted information may be more appropriate. One voluntary organisation believed that Chinese communities in particular are poorly catered for in terms of accessible information.

- Research results suggest that newer technologies, such as the internet, can offer both an alternative and a complement to traditional text-based products (7). The NHS Direct New Media report (1) suggests that some problems with the format of information may be overcome in part by paying attention to font size, colour, layout and plain English. Although the internet is increasingly being used as a channel for providing information, this is not an appropriate format for all groups, for example, those with the chaotic lifestyles associated with mental health problems, drug abuse or leaving prison. The voluntary organisations that were contacted in this scoping review believed that people with chaotic lifestyles often preferred printed formats. Nevertheless, it has also been shown that with training and support, some people who do not have home internet access could start to access information via community internet centres (6). However, one study showed that people with HIV/AIDS wanted what they considered safe environments where they could access information, for example, hospitals and other clinics (Anderson and Doyal, 2004). This may preclude the use of community resources.

For these groups of people, the correct format of information is particularly important. Appropriate formats include: written information on paper/leaflets/letters; information provided on the internet (with speech output or large screen/font size and with training/support); and translations that are also accessible verbally, not just in written form.

Government development projects are addressing some of these identified needs.

- For older people, the Partnerships for Older People Project initiatives (31) are the only initiatives that specifically focus on (and will evaluate) the effectiveness of using different formats for providing information. Many of these formats are verbal, with older people employed as networkers or wayfinders to pass on information by word of mouth. National and local evaluations of POPPs will consider the effectiveness and consequences of different ways of providing access to information. We do not know the full range of formats to be used in POPPs initiatives, or whether any will be in languages other than English.

- For visually impaired people, a Section 64 project is aiming to establish information and support services in eye clinics (21). We do not have any details about what information will be provided or how, and there is no known evaluation of this project. The project has only recently been funded and is due to report in 2009. It is likely, however, that this project will concentrate on providing information to people with visual impairments about services specifically for people with visual impairments, and so will not address the information needs of people with visual impairments who do not currently attend eye clinics or to people whose main needs lie elsewhere but who are also visually impaired.

- No government development projects were identified that are aimed specifically at improving access to information by BME communities.

- For those people with chaotic lifestyles (such as drug or alcohol abusers, people with HIV/AIDS and those with mental health problems), there are no ongoing or planned government projects that aim to improve their access to information. The Directory of Supporting People Services (41) is relevant to some people in these groups and has been put on the internet, but the evidence summarised above is that those with chaotic lifestyles do not often access the internet.

- Although many implementation projects are introducing information in a variety of formats, only one undertaking an evaluation, and that is limited to the number of requests for different formats. This is CSCI's guide 'Social Care – choosing the right service for you' (47). The guide will be sent in paper format to all councils in England but will be available also on CSCI's website and in alternative formats for disabled people and languages for those who do not read English. We are not aware of the different formats or languages to be offered, but the evaluation should show their relative popularity.

- Many DH Section 64 and other projects, particularly for older people, are aiming to provide information via the internet, leaflets or face to face (see, for example, 18, 19, 23, 26, 28, 30). None is evaluating preferences for or the relative accessibility of the different formats; indeed, all except the one stop shop on care home information (30) are developing only one format (that is, either a web page or a helpline). No projects address the issue of improving the accessibility of information provided on the internet for visually impaired people.

The needs that have been identified that relate to information formats but are not being addressed by government development projects therefore include:
- support in using the internet for people with visual impairments or chaotic lifestyles;
- the provision of verbal information for people who are visually impaired or whose literacy levels in English or other languages are poor; and
- information in appropriate formats for people with dual or multiple impairments.

#### *4.1.2 People want information that is easy to find without having to search numerous sources*

One gap that has been highlighted, in particular in the discussions with the voluntary organisations, is that people do not know where to go as the first port of call for information and do not know how to find information about how to access social care services. Government research findings also suggest that information should be signposted and branded appropriately so that its relevance to people is more obvious (9) (12).

- Some have suggested that a one stop shop (8) or resource centre (Thomas Pocklington Trust, 2003) that provides many kinds of information, advice and support in one place would be helpful. However, concerns have been expressed (by a voluntary organisation) that a problem with providing information services in one location is that they are often convenient for some people who may live locally, but are not so for others who live further afield or who are housebound. One stop shops that are internet-based could be an answer to making information easy to find without having to search numerous sources and without having to visit a physical location. However, this then introduces the problems of internet access for, for example, visually impaired people, older people and those with chaotic lifestyles.

Although only a small number of research projects suggested one stop shops as a method of improving access to information, many development projects are nevertheless aiming to implement one stop shops for information and advice.  Whilst the common theme is that one stop shops offer a range of diverse information from one access point, there is little consistency over the type of access point; it could be a web page, a helpline or a physical building.  Neither is there agreement on whether a one stop shop should provide information on all issues relevant to a defined user group, on all issues relating to a particular service type, or on all issues for all users of social care services.  Whatever definition is chosen, there are many one stop shops in existence already and others under development.

The majority of one stop shops identified in this review are web-based.  Twelve of the government implementation projects described are aiming to introduce or further develop internet-based information provision.  Half of these projects are generic, that is, aimed at all social care service users.  The remainder are user group specific, aimed at older people, people with dementia, people with long term neurological conditions and people with sensory impairments.  No projects were identified that are aiming to evaluate the effectiveness of different types or locations of one stop shops for different user groups.

The government-managed internet-based one stop shops highlighted in the implementation projects and described previously in the relevant sections are:

- The Directgov website (43 and 44) (see sections 3.4 and 3.1.1 respectively).  The Cabinet Office/Central Office of Information has overarching responsibility for this website which includes audience specific sections for over 50s, carers and disabled people.  DWP is responsible for all three of these sections and has recently redeveloped the over 50s section (44).  A current ODPM (now DCLG) project is ‘deep linking’ information on local authority websites from the Directgov site (43).  This means that the links from Directgov will go directly to the relevant information on LA web pages, rather than just to the LA home pages.

- ODPM (now DCLG) has recently put its Directory of Supporting People Services online (41) (see section 3.3).  This allows users as well as care managers/other intermediaries making referrals to search for services funded from Supporting People resources.  This information service is also accessible through the disabled people section of Directgov.

- ODPM (now DCLG) is supporting the roll out to all England of web-based fact sheets about local council services (42) (see section 3.4).  The fact sheet templates and handbooks to be sent to all councils in April 2006.  Using the fact sheets is optional, but if used, they will be available on local authorities’ web pages and will therefore be, in effect, local web-based one stop shops.

- The Partnerships for Older People Project (POPP) initiative (31) is evaluating a number of one stop shop type methods of imparting information, including using the internet, helplines and face to face methods (see section 3.1.1).

- National Library for Health (38) (see section 3.1.2). NHS Connecting for Health is aiming to produce a specialist neurology library for health and social care professionals and links from NHS Direct to recognised sources of high quality information for people with long term neurological conditions and their families.

The remaining projects to develop and implement web based one stop shops are managed by voluntary organisations. All are funded through DH Section 64 grants and have been described earlier. They are:

- Disability Alliance: Website Information Project (16)
- StartHere: Localised Countrywide Database project (24)
- Dementia Voice: English Development Centre Web Project (18)
- Trent Dementia Services Centre: National Information Resource of Assistive Technologies (26)
- SENSE: Technology Advisory Project (27)
- Elderly Accommodation Council: One Stop Shop for Care Home Advice (30)

None of the Section 64 funded projects have an evaluation element, so it will not be possible to judge how successful or appropriate these sources of information are, or, if they are, why this is the case. The POPPs initiatives, Directgov website and Supporting People online directory are all subject to ongoing evaluations that, between them, should be able to add to current knowledge about the usability of online software, quality of data, success in keeping information up-to-date of data, usefulness of information and ease of navigation through the categories in which information is presented. We are not aware of any developments or evaluations of internet-based one stop shops in languages other than English.

The information needs that have been identified but are not yet being addressed are therefore for:

- information about where and how to start in finding out about appropriate social care support; and
- improved awareness through better publicising and signposting of information sources.

### *4.1.3 People want personalised information*

The research evidence suggests that people want information that is personalised so that it is relevant to their specific social care needs.

- Two research projects highlighted the fact that people want information that is tailored to their personal circumstances, rather than having to search through a mass of more general information (8 and 9). This finding was supported by one of the research articles on intermediate stroke care that found that people wanted information focussed on issues relevant to them, rather than the acquisition of more general information as an end in itself (Robinson *et al*., 2005). In addition, Beverley (2004) and a voluntary organisation both made the point that people are not homogenous in their information needs, that is, the information requirements and accessibility issues for one visually impaired person may be very different from another's. Information that is focussed specifically on a person's needs is therefore the most appropriate.

The importance of engaging with the needs of the whole person in the provision of information is reinforced by findings in the Information Needs of Disabled People project (5) which highlighted the need to link information about specialist services and mainstream services, in a person-centric way. Whilst outside the specific focus of this review on information about social care services, at a local level, this implies improving links and signposting between social care information and information about other local services such as transport, leisure and cultural facilities.

A number of government development projects are addressing the issue of personalised information by developing information sources that are interactive and intelligent, that is, they allow people to give personal information and in return be provided with personalised information. These projects are:

- ODPM's (now DCLG's) online Supporting People Directory (41) which takes people through a series of questions about their needs and presents information about appropriate services in their area.
- DLF's SARA self-assessment tool (46). This is a web-based self-assessment questionnaire that is used to provide information about specialist low level equipment for disabled people.
- DH's Health Search Engine (35). This project is planned but has not yet begun. It will be linked to the information accreditation scheme (36) that will 'kitemark' providers of good quality information. The search engine will assist people in finding good quality information that is relevant to them.
- Smarter Working in Health and Social Care (32). This project, being carried out by the Centre for Aging Population Studies, is evaluating a self-administered questionnaire that is used to identify health risks and provide personalised advice on how to change behaviour.

The Supporting People Directory and the SARA self-assessment tool are both being evaluated for their usability as web-based tools. In addition, the Information Prescription (37), currently in the early planning stages, aims to provide personalised information to people newly diagnosed with a long term condition. The project will evaluate the provision of both paper-based generic information and personalised information about local services.

Each of these projects should help people to access more personalised and relevant information. In relation to housing, equipment and health care, therefore, the needs that have been identified are being met. However, there appear to be no similar developments in other areas of social care services.

### *4.1.4 People want targeted information at the right time*

Information should be targeted and timely. It should be targeted at appropriate groups who need the information but may not ask or know how to search for it, and it should also be made available to people at the times when it is actually needed.

- Some groups may be excluded from accessing information due to the format in which it is provided. People from ethnic minority communities may find information is not provided in accessible languages and older people may be more reticent in asking for information (Silveira and Allebeck, 2001). Other groups that the research evidence suggests have difficulty in accessing information and who could also be targeted include carers from BME communities, young carers and carers in rural areas (8).

- Information should also be provided at the time when it is most helpful, for example, prior to discharge from hospital (Joseph Rowntree Foundation, 2005) or release from prison (Mitchell and McCarthy, 2001). For some groups, such as disabled parents whose needs fluctuate, ensuring information is accessible before a crisis point is reached is essential (Wates, 2003). For others, targeted information would be helpful at the time of life transitions such as the onset of impairment or leaving education and moving into work (5).

Only one government implementation project will help address these needs.

- The Information Prescription project (37) will provide information to people at the time of their diagnosis with a long term condition. It will therefore target information provision at an appropriate time.

There are no other implementation projects that actively direct information at specific groups of people, taking that information to people rather than merely making it available, and no other projects to promote better timing of information provision.

The need to target information specifically at the following groups has been identified but is not yet being addressed by government development projects:
- people from ethnic minority communities, especially older people and carers;

- carers from rural communities and young carers;
- prison leavers at the time of their release; and
- people with fluctuating support needs, such as disabled parents, before they reach crisis point.

### *4.1.5 People want good quality information*

Users of information need to be assured that the information is kept up to date and is provided by experts.

- Government was seen as an acceptable and even desirable provider of information as long as information is kept up to date and is provided by experts (9).

- The longevity of information can be a problem. Information, such as contact details of service providers, can become out of date quickly.

- Some studies have found that people would like to see real life examples of how others are using certain services, for example people with mental health problems using direct payments (Joseph Rowntree Foundation, 2005), and case studies giving positive stories from disabled people that provide inspirational information (9).

Three government projects are addressing the longevity and updating of information. They have been described earlier but a brief overview is given here.

- The ODPM (now DCLG) /e-citizen Fact Sheet project (42) is an example of web-based information that can be updated more quickly and efficiently than paper based information. This project has developed templates for over 200 council-provided services (mainly social care but also environmental services). The fact sheets were developed originally by Oldham MBC in response to an audit of their own information provision which found that many leaflets were out of date, expensive to replace and difficult to take out of circulation.

- The DH Community Information Bank project (39) will begin in mid-2006. In this project, PCTs, LAs and others will work together to investigate how an integrated database of local services can be shared and kept up to date. The database will be accessed by information providers such as helplines rather than by the general public direct. It will provide information on, for example, support groups and care homes. Methods of keeping the database up to date will be tested.

- In addition, the DH Information Accreditation Scheme (36), which involves ‘kitemarking’ information providers, will be implemented by the end of 2007. It is not clear yet how the scheme will work or what the quality criteria will be, but the aim is to accredit providers of information rather than the information itself. This project will build on the findings of the Quality of Health Information project being undertaken by the Picker Institute (3). It should address the desire for information to be up to date and provided by experts.

We are not aware of any development projects that are aiming to improve the quality of information by including more positive personal stories or case studies.

A need that has been identified but is not yet being addressed by government development projects is:

- the use of positive case studies and inspirational stories from disabled people.

### *4.1.6 People want information from well trained staff*

This review specifically excluded projects that aimed primarily at informing social care management and front-line staff. However, as staff often play important 'gatekeeping' and referral roles, staff training is key.

- Social and health care staff are important sources of information (Beverley *et al*., 2004) (12) as are other information intermediaries such as voluntary organisations and families (5). Some projects have shown the importance to those accessing information of staff who know the issues and have the time to spend with clients (Joseph Rowntree Foundation, 2005). It has also been suggested that older people need the chance for written information to be backed up by discussions with an informed person (Help the Aged, 2000) and that staff giving information and advice at resource centres should be professionals (although the type of professional is not stated) (Thomas Pocklington Trust, 2003).

This evidence raises the issue of staff training to ensure that those who need to be are good and effective communicators. Two of the development projects do include an element of training for staff.

- The development projects that include an element of staff training are in the areas of learning difficulties (19) and dementia (26). The training mentioned in these projects is about improving staff knowledge about needs assessment and care/service planning. However, we do not have any details about whether or not these include training to improve a staff member's ability to impart information.

As identifying projects about staff training was not an aim of this review, we cannot say whether or not there is a gap in either knowledge or government activity, but we do know that people want to access information provided by well trained staff who have the time to discuss information with clients.

### *4.1.7 Services about which information is hard to find*

The research evidence suggests that access to information about both residential and domiciliary care services needs improving, and that the provision of information across organisational boundaries is not joined up.

- As well as general observations, such as information on care homes not always being easy to obtain (12), others have mentioned specific issues that relate to financial information. For example, Thompson and Wright's (2000) paper showed a lack of understandable information about the financial and legal status of relatives in relation to the liable relatives rule for paying for residential care. In relation to domiciliary care, evidence suggests that it is difficult to get information about local authorities' charging policies.

- One of the voluntary organisations interviewed commented on the difficulty of potential residents such as drug abusers in finding detailed information about residential care facilities, for example, whether or not they accept pets in combination with other needs such as wheelchair access.

- Two voluntary organisations (representing people with drug problems and those with mental health problems) pointed out that there are many people who would like to access services, such as counselling, but who are not referred through the NHS and cannot afford to pay for it themselves. Both organisations suggested that there should be more information available about free services or grants for accessing these services.

- Another frequently cited gap is the lack of joined up information provision about services across sectors. The research that looked at the content of the disabilities section of the Directgov website (9) found that people wanted an overview of the responsibilities of national and local governments, voluntary organisations and the private sectors. Robinshaw and Evans (2003) highlighted the frustration of parents of disabled deaf children that professionals and voluntary organisations did not direct them to alternative service provision in the private or voluntary sector. Information was provided predominantly about their own services. Likewise, Beverley *et al*. (2004) identified the lack of a co-ordinated approach between health, social care and other information providers, and the ODI's research into the information needs of disabled people showed that cross departmental information provision was not joined up (5).

Three development projects are addressing some of these issues.

- A current Section 64 project is aiming to develop a one stop shop for advice on care homes (30). This project aims to provide links to care home inspection reports but also ‘softer’ information such as the types of activities on offer. It may, therefore, address one of the information needs identified above, that is, information about residential care facilities. We do not know of an evaluation element to this project.

- Another Section 64 project aimed to improve access to information about charges (28), although this project related to community care charges only, not those for residential care.

- The Community Information Bank (39) is investigating the development of an integrated database of local services and therefore may begin to address the provision of information across service boundaries.

A need that has been identified but is not being addressed is therefore:

- the need to increase the accessibility to potential users of information about free services or information about help towards paying for services privately.

### *4.1.8 Ongoing/planned government projects to further investigate needs for information*

Four ongoing or planned government-related research projects are investigating further the information needs and accessibility of information about social care services.

- A part of the evaluation of individual budget pilots will consider the availability and accessibility of information in relation to support planning (2). The results should add to the overall picture presented here of availability and personal usefulness of information.

- The Picker Institute is currently assessing the quality of information provided about certain medical conditions (3). It is not clear whether or not this study will include information about social care services for people with these conditions. The study should show what constitutes good quality information provision.

- The NSF for Long Term Conditions Information Strategy which was published in 2005 proposed investigations into people’s needs for information and how information can be made available; appropriate formats and timing of information provision; and how staff can be helped to meet people’s information needs (4). If undertaken, this research should add further understanding to many of the issues raised above.

- The ODI project on Information Needs of Disabled People is ongoing (5). Phase 1 is about to be completed and will report on the demand for and supply of information on services for disabled people in all government areas. Phase 2 will use the findings on needs to improve information provision.

## 4.2 User groups and social care service types for which there is no evidence about the accessibility of information

This section highlights the user groups and social care service types for which we have little or no evidence about the accessibility of information.

There is little or no knowledge as a result of government research projects or from the recent research literature on the accessibility of information about some types of social care services, namely:

- short breaks and respite care;
- day care and daytime activities; and
- equipment and assistive technologies.

There is no evidence in these areas about what kinds of information wanted by different groups of (potential) service users, the formats they find most accessible, where information should be provided or how it is best accessed. In each of these areas, research is needed to fill these knowledge gaps. (Some government development projects, however, are aiming to increase access to information about equipment and assistive technologies, for example the DLF SARA self-assessment tool (46). It is not clear what the research evidence is about people’s information needs and preferred methods of accessing information about equipment and assistive technologies; this evidence may be identified in written reports from these projects.)

In addition to these three clusters if services, there is little evidence about the role and effectiveness of social care and other staff in providing accessible information about social care services. It was not the aim of this review to identify research or development projects about staff training, but there does appear from the evidence in general to be a desire to receive information from effectively trained staff.

Finally, the extent to which private purchasers of social care services are catered for in terms of accessible information is not clear. We do not know if private purchasers have the same access to information about social care services as those people who receive social services funded support; if they want access to information via social care services; or what information is available currently and from where.

# 5. Discussion and conclusion

This scoping review identified a total of 47 recent, current or planned government-related projects that are addressing the accessibility to users and carers of information about social care services. Eleven were research projects to investigate the information needs and accessibility of information about social care services to users and their carers. Thirty-six were development projects aiming to improve the accessibility of information about some or all social care services to some or all groups of users. Two-thirds of all the projects identified are being undertaken by or are otherwise associated with the Department of Health (including time limited projects funded through Section 64 grants). One or two projects are being undertaken by each of the Office for Disability Issues, Department for Education and Skills, Social Care Institute for Excellence, National Centre for Independent Living, Disabled Living Foundation and Commission for Social Care Inspection. The Office of the Deputy Prime Minister (now the Department for Communities and Local Government) and the Department for Work and Pensions each has four of these projects.

The review of government-related projects was limited to ongoing or planned projects, or those recently completed, that were undertaken in England. Projects that were completed prior to 2005 or that were undertaken in other parts of the UK are therefore not included. For example, some projects that may provide useful insights but were based in Scotland or Wales have not been included (see Leece and Bornat (2006) for examples). This was not a systematic review and we did not attempt to identify ongoing research from ‘research in progress’ registers. The fact that information for this review was collected verbally from contacts in government departments, using a snowballing technique (asking respondents to suggest new contacts), may also mean that some projects have not been identified. However, we are confident that the wide range of contacts made; the fact that many projects were identified by more than one contact; and that no new projects were identified by the final contacts spoken to, has resulted in a thorough investigation. In addition, our literature search identified 18 articles that investigated, at least in part, the information needs and accessibility of information on social care services for different groups of users and carers. We also spoke to representatives from six voluntary organisations in order to ascertain their views about the accessibility of information about social care services and, in particular, any gaps in the information that is available.

Overall, a greater than expected number of development projects has been identified, but the lack of research and evaluation projects is striking. Not only have a limited number of government-related research projects been identified, but, where the literature was searched, usually only one or two relevant papers in each topic area were identified. This is in part because the search was limited only to papers published in three databases since 2000. Nevertheless, those papers that were identified rarely focussed solely on information needs about social care services; most included people’s information needs and the accessibility of information as part of a wider research remit.

In addition, it is not clear in some cases what research evidence the development projects are based on. For example, although some of the voluntary organisations that were contacted for this research suggested that service users want a single source or first point of call for information, we have identified limited research evidence in support of one stop shops. Nevertheless, five government projects to further develop internet-based one stop information shops have been identified, as well as six Section 64 funded projects. Part of the reason for the lack of evidence may be a consequence of the methods used in this review; where our informants were not undertaking research themselves (this is the case in particular for Section 64 projects), they were not always able to give details of the evidence on which the development projects were based. The original proposals for these projects and indeed the final reports should provide the research evidence, but we have not based our findings on these reports.

Many development projects (again, Section 64 funded projects in particular) do not appear to have an evaluation element. Therefore, even when these development projects are completed, they will not provide evidence on the effectiveness or appropriateness of the methods, of providing information and improving its accessibility, that they have been developing. In addition, the projects funded through Section 64 grants are time limited. Therefore, not only is it unlikely that there will be evidence about the effectiveness of these developments at the end of the projects, but neither will there be any guarantee that they will be able to continue at the end of the funding even if they prove to be successful.

The government-related research projects and the research papers identified from the literature highlighted the information needs and problems in accessing information that some groups of people have. Whilst many of the government development projects identified were already addressing these issues, some information accessibility issues do not yet appear to be addressed. The gaps in known information needs that are not being met are the specific information needs and accessibility issues associated with people from black and minority ethnic communities; with chaotic lifestyles (such as people who have just left prison or are drug or alcohol users); with fluctuating support needs; with visual impairments; with multiple impairments; and who are private purchasers of social care services.

In addition, there is little or no evidence, either from government research projects or from the recent literature, on the accessibility of information about some types of social care services. We have no details about the accessibility of information about short breaks and respite care; day care and daytime activities; or equipment and assistive technologies.  (Some development projects, however, are aiming to increase access to information about equipment and assistive technologies.) Research is therefore needed to fill the knowledge gaps in these areas.

Users need to know that information is accurate, up-to-date and useful for them.  The patient information prescription and accreditation scheme will go some way to achieving this for patients newly diagnosed with certain long term conditions. However, it should also be noted that information needs change over time and information provided at the time of diagnosis will not be sufficient for subsequent needs.  Many of the other development projects identified may improve the accessibility of information to some users about some social care services, but will also increase the already vast range of sources of information available, without necessarily helping people to differentiate between sources that are reliable, evidence-based and up-to-date, and those that are not.

The internet appears to be the dominant form of one stop shop.  Internet-based information sources have many advantages: they can be updated quickly and efficiently; they can be accessed at any time and from any computer; and they can include large databases of information that cover all parts of the country.  However, they also have their disadvantages: not everyone who needs the information has access to a computer; some people are not proficient in the use of the internet; and for some people their impairment makes using a computer without additional support difficult.

In addition, whilst many development projects are aimed at specific groups of service users (for example people with dementia or people with visual impairments), many people have dual or multiple support needs.  For example, an older person may also be a carer or a person from a BME group may also have sensory impairments. These multiple support needs translate into multiple information needs.  It is important therefore that people are able easily to access information for different needs and about different social care services.  The range of information that is accessible through a single source is therefore important.  Internet-based one stop shops may be one such source.  However, whilst, for example, some people may be able and willing to use the internet, older people or those with visual impairments may not have the necessary expertise, dexterity or other support facilities to enable them to do so.  Furthermore, people within specific groups may have different preferences for the format in which information is provided.  For example, younger people from BME groups may be happy and able to access information in English via the internet, but older people from BME groups may find verbally provided information in another language more accessible.  Thus the importance of providing information in a number of formats is evident.

Several research studies concluded that older and disabled people wanted information from professionals and also wanted to use existing health and social care service organisations as information points.  However, few development projects are aiming specifically to introduce or enhance information services in health care clinics or social care facilities.  In addition, although this review did not investigate information-related training for professionals, few of the development projects identified include an element of staff training.  The collection of evidence about the role and effectiveness of professionals in imparting information about social care services and, if necessary, identifying and developing appropriate training to improve professionals' ability to impart such information effectively, is important; they are often the gatekeepers to new services, but may not be knowledgeable about those services outside their direct remit or provided by other organisations.

It is not clear for many research and development projects whether the information needs of people who purchase social care services privately have been addressed. Many people may have assets that preclude them from receiving social care services funded by statutory agencies.  This is a substantial group that includes, for example, older people seeking residential or domiciliary care and people of all ages who need equipment to support them in their everyday lives.  People wanting short break/respite care may also purchase privately.  Other services such as cleaning, gardening and minor repairs also fall into this category.  Research evidence has highlighted confusion about the liable relatives rule for residential care and a lack of information about fair charging for domiciliary care.  Although the project by the Disability Alliance (which aims to provide explanations of the legal position on charging for community care services to help allay people's fears about the cost of services) will help to plug this gap, further research on the accessibility of information for private purchasers of social care services is needed.

# 6. Recommendations

One of the aims of this scoping review was to identify any gaps in knowledge or government activity where future research might be needed. This section highlights these areas.

There is currently no research evidence on the accessibility of information about:

- short breaks and respite care;
- day care and daytime activities; and
- equipment and assistive technologies.

Research on the accessibility and use of information should be undertaken in these areas.

Information needs among the following groups of people have been identified but are not yet being addressed by government development projects:

- people from ethnic minority communities, especially older people and carers;
- carers from rural communities and young carers;
- information for people with multiple impairments;
- people with fluctuating support needs, such as disabled parents, before they reach crisis point;
- prison leavers at the time of their release and other people with chaotic lifestyles;
- private purchasers of social care services (including the need to increase the accessibility of information about free social care services and information about help towards paying for services privately).

The following formats and methods of providing information have been identified as helpful or desirable by service users and their carers, but are not currently being implemented in development projects:

- support in using the internet for people with visual impairments or chaotic lifestyles;
- the provision of verbal information for people who are visually impaired or whose literacy levels in English or other languages are poor;
- better signposting of information sources, in particular information about where and how to start in finding out about social care services;
- personalised information in areas other than health care, equipment and housing services;
- the provision of information by social care staff and other professionals; and
- the use of positive case studies and inspirational stories from disabled people.

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# Appendix 1 List of contacts

The list below gives all the people who were contacted to find out about government-related research and development projects. We thank each of these people for their help in providing information for this review.

**Department of Health**

Ann Barker, Women's Health and Maternity Team
Sarah Bird, Social Care Information
Clare Brassington, NSF for Long Term Conditions
Phil Cohen, Policy Communications
Juliet Gogo, NSF for Long Term Conditions
Kate Hardy, Mental Health and Older People
Andrew Harvey, Skills for Health
Pauline Heather, Disability and Carers Analysis Division
Alison Langridge, Policy Communications
Nick Marcangelo, CSIP
Mary Mulvey, Learning Disability
Rachel Neaman, Communications
Tricia Nicholl, Valuing People Support Team
Emma Pryke, Multi-Media Information Service
Graham Reid, Information for Choice
Ian Salt, ICES (Integrated Community Equipment Stores)
Mary Simpson, Information for Choice
Helen Steele, Older People and Disability
Helen Tomkys, Older People and Disability
Raphael Wittenberg, Care Services Analytical Team

**Department for Education and Skills**

Jacqueline Shurlock, Skills and Education Network

**Department for Work and Pensions**

Debbie Hopwood, Directgov/Link Age Plus
Jacquie Wood, Directgov

**Office for Disability Issues**

Grahame Whitfield
Roger Wicks, Information Needs of Disabled People Project

**Office of the Deputy Prime Minister (now Department for Communities and Local Government)**

Lilian Barton, e-Citizen Project Board Member
Jon Boland, Hub Services

Cathy Cant, e-government Standards/Linking LA Systems
Andrew Keen, Capacity Building and Strategy Team
Ian Laughton, Nomad
Gill Moffett, Social Exclusion Unit

**Central Office of Information**
Wendy Gregory, Head of Information
Gill Carruthers, Research Department

**The Information Centre for Health and Social Care**
Roger Staton, Adult Social Care Information Development (ASCID) programme
Ursula Turner, ASCID programme

**Commission for Social Care Inspection**
Frances Hasler, Head of User and Public Involvement

**Disabled Living Foundation**
Dave Clarke, SARA Self-Assessment Tool

**Other**
Heather Billingham, Action for Blind People
Jenny Morris, Jenny Morris Consulting

# Appendix 2 Checklists for interviews

Checklists used in government and voluntary sector interviews, and used as a basis for literature searches.

**Checklist for information for user groups**

- Physically disabled people
- People with hearing or visual impairments
- People with learning disabilities
- People with mental health problems
- People with multiple service needs/long term conditions
- People with HIV/AIDS
- Drug and alcohol users
- Older people
- Black and ethnic minority groups
- Carers/informal providers.

**Checklist for information about range of services**

- Advice and information centres
- Residential care (including charging policies)
- Domiciliary care
- Respite care
- Day centres/daytime activities
- Intermediate care
- Provision of equipment (including assistive technology)

**Checklist for information about providers of services**

- Public provision
- Private providers
- Formal/voluntary providers
- Informal/community provision.

**Checklist for format of information provision**

- Written information (on paper or the internet)
- Verbal information (via phone helplines or drop-in centres)
- Languages available.

# Appendix 3 Literature search strategy and search terms

On Social Care Online all the searches were conducted using ‘free text’, which searches the whole record on the system (title, abstract, publisher, journal title, topics, etc) but not the full text of the document. On the CSA Illumina databases (ASSIA and Social Services Abstracts), the title, abstract, and descriptors were searched. However to limit the results on these databases to a manageable number for people with mental health problems (set 1.8), the strategy was revised to search the title only, and the USA and Canada were excluded from the search (i.e. not USA or America* or Canad*).

Set 1.1: *Black and minority ethnic groups*
- black and minority ethnic group*
- BME
- minority ethnic
- ethnic minorit*
- racial minorit*
- minority group*
- ethnic group*
- racial group*
- ethnicity

Set 1.2: *Day centres or daytime activities*
- day centre*
- daytime activit*
- day care
- daycare
- day hospital*

Set 1.3: *Domiciliary care*
- domiciliary care
- home care
- homecare
- domiciliary service*
- home help*
- home service*

Set 1.4: *Drug or alcohol users*
- drug abuse*
- drug use*
- drug depend*
- drug addict*
- drug misuse

- substance abuse*
- substance depend*
- substance misuse
- alcohol abuse*
- alcoholic
- alcohol use*
- alcohol consumption
- alcohol misuse
- drinking
- alcohol depend*
- alcohol related problem*

Set 1.5: *Equipment or assistive technology*
- equipment
- assistive technolog*
- adaptation*
- technical aid*

Set 1.6: *People with HIV/AIDS*
- HIV
- human immunodeficiency virus
- AIDS
- acquired immune deficiency syndrome

Set 1.7: *Intermediate care*
- intermediate care
- community care
- rehabilitation
- hospital at home

Set 1.8: *People with mental health problems*
- mental health*

Set 1.9: *Respite care or short breaks*
- short break*
- respite

Set 1.10: *Sensory*[1]
- sensory impair*
- visual* impair*
- vision impair*

---

[1] The terms 'blind' and 'sight' were not included as search terms since they produced irrelevant results such as 'blind alley', 'at first sight', etc.

- hearing impair*
- hearing loss
- hearing problem*
- partially sighted
- deaf*

Set 2:
- information

Set 3:
- social care
- social service*
- social welfare
- social support*

# Appendix 4 Articles identified in literature searches

| | Database | Results | Duplicates | After de-duplication | Potentially relevant | Included in review |
|---|---|---|---|---|---|---|
| **Black and minority ethnic groups** | ASSIA | 6 | 0 | 6 | 0 | 0 |
| | Social Services Abstracts | 15 | 0 | 15 | 1 | 1 |
| | Social Care Online | 13 | 3 | 10 | 2 | 0 |
| | All | 34 | 3 | 31 | 3 | 1 |
| **Day centres or daytime activities** | ASSIA | 2 | 0 | 2 | 1 | 0 |
| | Social Services Abstracts | 3 | 1 | 2 | 0 | 0 |
| | Social Care Online | 6 | 2 | 4 | 0 | 0 |
| | All | 11 | 3 | 8 | 1 | 0 |
| **Domiciliary care** | ASSIA | 6 | 0 | 6 | 1 | 0 |
| | Social Services Abstracts | 3 | 2 | 1 | 0 | 0 |
| | Social Care Online | 12 | 1 | 11 | 4 | 4* |
| | All | 21 | 3 | 18 | 5 | 4 |
| **Drug or alcohol users** | ASSIA | 15 | 0 | 15 | 3 | 1 |
| | Social Services Abstracts | 30 | 4 | 26 | 3 | 0 |
| | Social Care Online | 21 | 3 | 18 | 0 | 0 |
| | All | 66 | 7 | 59 | 6 | 1 |
| **Equipment or assistive technology** | ASSIA | 9 | 0 | 9 | 0 | 0 |
| | Social Services Abstracts | 5 | 0 | 5 | 0 | 0 |
| | Social Care Online | 16 | 1 | 15 | 3 | 0 |
| | All | 30 | 1 | 29 | 3 | 0 |
| **People with HIV or AIDS** | ASSIA | 11 | 0 | 11 | 4 | 1 |
| | Social Services Abstracts | 25 | 6 | 19 | 1 | 1 |
| | Social Care Online | 15 | 7 | 8 | 0 | 0 |
| | All | 51 | 13 | 38 | 5 | 2 |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Intermediate care** | ASSIA | 19 | 0 | 19 | 8 | 2 |
| | Social Services Abstracts | 8 | 1 | 7 | 1 | 1 |
| | Social Care Online | 46 | 5 | 41 | 4 | 0 |
| | **All** | **73** | **6** | **67** | **13** | **3** |
| **People with mental health problems** | ASSIA | 57 | 0 | 57 | 2 | 1 |
| | Social Services Abstracts | 54 | 13 | 41 | 4 | 1 |
| | Social Care Online | 56 | 7 | 49 | 4 | 2 |
| | **All** | **167** | **20** | **147** | **10** | **4** |
| **Respite care or short breaks** | ASSIA | 4 | 0 | 4 | 0 | 0 |
| | Social Services Abstracts | 3 | 2 | 1 | 0 | 0 |
| | Social Care Online | 2 | 1 | 1 | 0 | 1 |
| | **All** | **9** | **3** | **6** | **0** | **1** |
| **People with sensory impairments** | ASSIA | 2 | 0 | 2 | 2 | 2 |
| | Social Services Abstracts | 4 | 1 | 3 | 2 | 1 |
| | Social Care Online | 13 | 2 | 11 | 2 | 2 |
| | **All** | **19** | **3** | **16** | **6** | **5** |

* one reference relates to residential care but was generated from the domiciliary care search.

# Appendix 5 Voluntary organisations from which managers interviewed

A member of the information management or helpline staff from each of the following voluntary organisations helped by talking over the telephone about the types of social care and other services that people want. They also talked about user groups that did not often ask for information and advice, and information that was hard to find.

Action for Blind People
Carers UK
Counsel and Care
Drug Scope
Mersey Neurological Trust
Mind.

We would like to thank these organisations for their help.

# Appendix 6 Titles of government-related research and development projects

This table gives the titles of projects, by government department and whether the project is predominantly:

- a research project to investigate information needs; or
- a development project to implement new methods of increased access to information.

| **Department** | **Projects that investigate access to information/ information needs (mainly research projects)** | **Projects that aim to improve access to information (mainly development projects)** |
|---|---|---|
| ***DH*** | | |
| • Recently completed | Patient Information Bank: Exploring Accessible Formats [1] | *Section 64 grants*<br>DIAL Raising Quality and Achieving Accreditation [13]<br>Disabled Parents' Rights Handbook [14]<br>Health and Social Welfare Project [15]<br>Website Information Project [16]<br>Which Powered Wheelchair [17] |
| • Current | Individual Budget Pilots Evaluation (SPRU, PSSRU, SCWRU) [2]<br>Quality of health information for patients and public (Picker Institute) [3] | *Section 64 grants*<br>Dementia Services Development Centre Web Project [18]<br>Elders Project [19]<br>Epilepsy Information Network [20]<br>Eye POD/National Eye Clinic Support Project [21]<br>Health Information Project [22]<br>Housing Adaptation Advisory Service Project [23] |

|  |  |  |
|---|---|---|
|  |  | Localised Country-Wide Database Project [24]<br>My Pregnancy, My Choices [25]<br>National Information Resource of Assistive Technologies for People with Dementia [26]<br>Technology Advisory Project [27]<br>Understanding Community Care Charges [28]<br>*Other*<br>Information Access Project [29]<br>One Stop Shop for Care Home Advice for Older People [30]<br>POPPs – Partnership for Older People Projects [31]<br>SWISH - Smarter Working in Social Care and Health [32]<br>Valuing People Support Team [33] |
| • Planned/ proposed | – NSF For Long Term Conditions Information Strategy [4] | Carer's Helpline [34]<br>Health Search Engine [35]<br>Information Accreditation Scheme [36]<br>Information Prescription [37]<br>National Library for Health for Specialist Libraries Information Support – Neurology [38]<br>Community Information Bank [39]<br>Social Care Link [40] |

| | | |
|---|---|---|
| ***ODI*** | | |
| • Recently completed | | |
| • Current | Information Needs of Disabled People Project [5] | |
| ***DfES*** | | |
| • Recently completed | UK Online Centres – supporting delivery of e-government services (SQW & MORI) [6] | |
| ***ODPM (now DCLG)*** | | |
| • Recently completed | Improving Services, Improving Lives [7] | |
| • Current | | Directory of Supporting People Services [41]<br>Fact Sheet E-Citizen project [42]<br>Local Directgov Programme – Connecting local authorities to Directgov [43] |
| ***DWP*** | | |
| • Recently completed | Carers' Information Needs – A Review [8]<br>Directgov Disabled People and Carers' Franchise – Customer Information Qualitative Research [9] | |
| • Current | | Directgov website – over 50s section [44] |
| • Planned/ proposed | | Link Age Plus [45] |
| ***SCIE*** | | |
| • Recently completed | Knowledge Review on Support for Disabled Parents [10] | |
| ***NCIL*** | | |
| • Recently completed | Wider Option – report of research project into intensive support schemes for direct payments [11] | |

| | | |
|---|---|---|
| ***DLF*** | | |
| - Current | | SARA self-assessment tool [46] |
| ***CSCI*** | | |
| - Recently completed | Information Sources Market Research Presentation [12] | Social Care – Choosing the right service for you [47] |

# Appendix 7 Summary details of research and development projects

## Summary details of research projects/other initiatives to investigate access to information

## Department of Health (DH)

### Recently completed

Project Number: 1
Title: Patient Information Bank: Exploring Accessible Formats
Dates: Completed early 2006
Organisation: NHS Direct New Media

Summary:

- NHS Direct New Media is developing a ‘Patient Information Bank’ on behalf of the DH. This is a bank of quality assured, evidence-based health information leaflets and fact-sheets that all health professionals in the NHS could use for and with their patients. Although health information dominated, social care information is not excluded.
- The objectives of this project to explore accessible formats were to (1) gain expert and lay input into the best way to provide accessible information through a consensus development panel, and (2) to undertake a brief literature review to explore relevant accessibility issues.
- Findings from the consensus development panel suggest that:
    - it is people who have sensory impairments, learning disabilities, dexterity problems or literacy problems who are most likely to have difficulty in accessing information in standard formats;
    - people with language barriers need translation and interpretation services, and the main languages needed may change over time;
    - if not all health professionals use the information bank, this may increase inequalities in access;
    - patients and voluntary organisations may be able to access the bank themselves in the future.
- Findings from the literature review suggest that the main accessibility barriers to effectively using health information are related to socio-economic factors, sensory impairments, learning difficulties, a lack of basic literacy skills and an inability to read English. These may be overcome in part by increasing internet access, paying attention to font size, colour, layout and plain English, and ensuring appropriate and effective translations.

### Current

Project Number: 2
Title: Evaluation of Individual Budget Pilots
Dates: Ongoing, in early stages
Organisation: PSSRU, SPRU, SCWRU (DH commissioned evaluation)

Summary:

- Individual budgets aim to offer people entitled to social care and/or other services greater transparency, choice and control over how their needs are met and enable them to access a wider range of services than currently possible.
- The aims of the evaluation of individual budgets include assessing the effectiveness of different models of individual budgets and the experiences of different user groups. The groups covered in the 13 English pilot projects are older people (including those with dementia), physically disabled and sensory impaired people, and people with learning disabilities, mental health problems and long term conditions.
- One element of the evaluation will involve a sample of individual budget holders who will be interviewed two months after being offered an individual budget. As part of this interview, individuals will be asked about the information they wanted, were able to obtain, and used to help in planning their support packages.

Project Number: 3
Title: Quality of health information for patients and public
Dates: 3 month project, due for completion April 2006
Organisation: Picker Institute

Summary:

- To produce an estimate of the number and types of information providers offering information about specific diseases or conditions (COPD and arthritis), well being (healthy eating), and a topical public health issue (e.g. MMR or avian flu).
- To obtain copies of relevant information materials and apply a defined set of criteria to determine their quality.
- To make an assessment of the likely overall impact of making better information available to patients, carers, health and social care staff, and members of the public.
- To carry out a cost-benefit analysis of the proposed accreditation scheme (carried out separately by DH economists).

  [See Information Accreditation Project in ‘initiatives to improve access’ section.]

### Planned/proposed

| | |
|---|---|
| Project Number: | 4 |
| Title: | NSF for Long-term Conditions Information Strategy |
| Dates: | March 2005 (published) |
| Organisation: | DH |

Relevant aims include:

- What information does the general public need about long-term neurological conditions and how can it be made available?
- What can be done so that people can obtain accurate and up-to-date information, in suitable formats, at a point of need, about the long-term neurological condition that they or someone in their family have been diagnosed with and about other services that are available to help them?
- How can information technology in the NHS be applied to help individuals at all stages to exercise choice in how to manage their condition and live independently in society?
- How can health professionals be helped to meet these needs of their patients and their patients' families and carers?

## Office for Disability Issues (ODI)

### Recently completed

None identified.

### Current

| | |
|---|---|
| Project Number: | 5 |
| Title: | Information Needs of Disabled People Project (Phase 1) |
| Dates: | Phase 1 October 2005 - April 2006 |
| Organisation: | ODI |

Summary:

- Project resulting from recommendations in *Improving Life Chances for Disabled People*.
- Looks at the information needs of disabled people in all areas of government. General aim is to improve information across government, to look for best practice in central and local government, and to look at where efficiencies could be made.
- Phase 1 of the project has three stages:
  - the demand for information: A literature review to determine what is known from government and academic research on disabled people's experiences and information needs;

  - the supply of information: Mapping services supplied to disabled people by central and local govt and the role of the voluntary sector;
  - to produce recommendations to explore demand and supply issues further and to get more information on the users' experiences.
- Results from the literature review suggest, amongst other things, that there is a lack of, or misleading, information; information is fragmented where individuals must access different forms of support and cross-departmental information is not joined up; and intermediaries such as the voluntary sector and families play an important role.
- Results of the mapping of information services will show which department manages each service, what the service is about, and the channels through which information is provided, e.g. online, helplines, leaflets.
- Recommendations for Phase 2 of the project will finalised by summer 2006. These will include both short term measures to improve information provision and more strategic ideas to embed the importance of information in services.
  Short term recommendations will cover areas like:
  - clearer and more transparent branding of information services;
  - improved signposting between the voluntary and public sector; and,
  - embedding good practice in many of the initiatives discussed in this report.

  Ideas to secure more strategic change will cover issues like:
  - engaging more fully with disabled people so their views are incorporated in future activity;
  - embedding the information needs of disabled people in broader communications strategy across government and the public sector; and,
  - producing a business case that argues for better information provision and setting out the implications for disabled people and service delivers where information is not prioritised.

**Planned/proposed**

None identified.

## Department for Education and Skills (DfES)

### Recently completed

| | |
|---|---|
| Project Number: | 6 |
| Title: | UK Online Centres.  Supporting delivery of e-government services. |
| Dates: | Report published February 2005 |
| Organisation: | SQW limited and MORI Social Research Institute (Commissioned by DfES) |

Summary:

- To investigate:
  - the existing demand for e-government services, and the potential of UK online centres to stimulate increased use;
  - the willingness and ability of UK online centres to support users in accessing e-government services.
- To run a pathfinder project to explore the potential of UK online centres to support the effective design, delivery and promotion of around 40 e-services delivery of e-government services by engaging their users in nine areas - older people, benefits for working age people, job search, family e-learning, sole-traders, community engagement, citizenship, rural services, and Directgov.

Results:

- 90 per cent of centres are willing and able to provide learning, access and support for delivery of online government services.
- 86 per cent of centres have a suitable infrastructure in place to do so.
- 45 per cent of the population have visited their local library, college or community centre to access information in the last year.
- If a library or learning centre offered help and training in how to use online services more generally, 20 per cent of all respondents say they would use these online services at the library or centre, and 14 per cent would learn how to use them at the library or centre, and would then use them at home or elsewhere.
- 56 per cent of users claimed they would use a ‘one-stop’ government website at their local UK online centre if they were offered basic help and training in how to use it.  A further 30 per cent claimed they would learn how to use the service at a UK online centre, but would then access this website elsewhere.
- 29 per cent of users said they would use their UK online centre more often if this support were available.

Pathfinders:

- Over the course of the project, more than 3,600 new users were introduced to e-government services, a figure which, when extrapolated across the entire UK online centre network, suggests the potential to deliver more than one million new users of e-government services over the course of a year.

- 50 per cent of users said that they would definitely use e-government services again. There were three principal reasons for this positive reaction: easy access to information; the relevance of the information; and the convenience of the services. UK online centres played a critical role in fostering these responses.
- From the research, three business models have emerged to support departments to increase take up of their e-government services: low intervention; high intervention; and a specific outcomes model. Ufi is currently working with individual departments and Directgov to identify which model best suits their particular range of e-government services.

### Current

None identified.

### Planned/proposed

None identified.

## Office of the Deputy Prime Minister (ODPM (now DCLG))

### Recently completed

Project Number: 7
Title: Improving Services, Improving Lives. Evidence and key themes. A Social Exclusion Unit Interim Report
Dates: Published October 2005
Organisation: ODPM

Summary:

- Improving Services, Improving Lives is a work programme consisting of five integrated projects. Its overall objective is to make public services more effective for disadvantaged people, in order to improve their life chances.
- There were five projects: disadvantaged adults; inclusion through innovation; young adults with troubled lives; excluded older people; and disadvantaged people who move frequently. The projects focussed mainly on health, education and training, employment and benefits, and housing. They also looked briefly at social care.
- One chapter of the interim report focuses on information and communication.

Results show that:

- Information from services can be hard to find and difficult to understand; it may be unavailable, inaccessible or inappropriately marketed. This affects disadvantaged people’s ability and willingness both to take up their rights to services and to fulfil responsibilities associated with them. Having the right information is also an essential precondition of user empowerment and choice.

- The general principles that underpin good practice include:
  - getting the basics right – making information easier to understand so that everyone using public services benefits;
  - understanding customers – involving people and working with partners to get effective and efficient results; and
  - using new technologies and outreach – either to complement or to provide an alternative to text-based products.

**Current**

None identified.

**Planned/proposed**

None identified.

## Department of Work and Pensions (DWP)

**Recently completed**

| | |
|---|---|
| Project Number: | 8 |
| Title: | Carers' Information Needs – A Review |
| Dates: | Completed January 2006 |
| Organisation: | DWP |

Summary:

- The in-house review was carried out because of awareness that carers' information needs are highly individual and unpredictable, their desire and need for information may be different, lack of information results in difficulty in making informed decisions, and a lack of knowledge may result in carers not receiving services to which they are entitled.

- The review included the following findings:
  - carers found that sources of help and advice were difficult to access and use and several sources had to be consulted;
  - particular problems were found for black and minority ethnic carers, young carers, carers in rural areas and former carers. Male carers were more likely to receive information than female carers;
  - carers found particular difficulty in accessing information if they were providing care for disabled children, people with a mental illness, learning disability or physical disability;

  - information was provided by health and social services, carer centres and job centres;
  - carers had particular difficulties accessing information on state benefits, pensions, paying for long term care or the side effects of medication;
  - a third of carers have access to the internet at home or work but time constraints act as a barrier to use;
  - the following were suggested as ways of providing information: one stop shop, personalised advice, information packs and directories, carers support workers, courses, and telephone groups.

| | |
|---|---|
| Project Number: | 9 |
| Title: | Directgov Disabled People and Carers' Franchise - Customer Information Qualitative Research |
| Dates: | Completed April 2006 |
| Organisation: | The People Partnership, for DWP |

Summary:

- The project explored responses to the current content on the Disabilities Section of the Directgov website. Within this, it aimed to identify how information content could potentially be enhanced and to produce information content guidelines for the future. Specific objectives were to explore:
  - 'life transitions' as a way of structuring information;
  - customisation/relevant transactions;
  - the relevance of specific information items;
  - navigation/information issues in relation to core information journeys.
- 12 two hour group discussions and 24 one hour in-depth interviews were held with people between 18 and 65 with sensory or physical disabilities from three areas of England.
- Conclusions and recommendations include:
  - the current website is felt to offer a great deal of very useful information;
  - the need and desire for there to be a separate section of the Directgov site which contains information relevant to all those with a disability/medical condition;
  - although the current content of the disabilities section covers a very broad spectrum of information needs, this is not immediately apparent from the current branding which suggests relevance for more severe disabilities;
  - it is acceptable, indeed desirable, for government to provide information/support relating to a much wider range of everyday life topics and, within this, to communicate the infomation in a much 'warmer'/closer/adult to adult/more customised fashion;
  - limits to acceptable information from government are imposed if people feel government do not have sufficient expertise or resources, or if the

    information/support in question may directly result in a negative personal consequence (for example not up to date or accurate);
  - suggestions for improvements include more articles written from the perspective of the disabled person, easy navigation around choices, providing inspirational information (for example positive case studies), giving overviews of the responsibilities of government/local authorities/voluntary organisations/private sector in relation to support, and providing the ability to customise information.

**Current**

None identified.

**Planned/proposed**

None identified.

## Independent organisations

### Social Care Institute of Excellence (SCIE)

| | |
|---|---|
| Project Number: | 10 |
| Title: | Knowledge Review on Support for Disabled Parents |
| Dates: | Ongoing |
| Organisation: | National Family and Parenting Institute with Family Welfare Association, Norah Fry Research Centre, Michele Wates and Jenny Morris |

Summary:

- This is a review of the literature and a practice survey that will be available in May 2006.
- The aims of the project include a review, amongst other things, of:
  - the views of disabled parents and the need for choice, independence and support in carrying out their role as a parent, including their experiences of access to mainstream support services, involvement in assessments of need, lack of flexibility of services and the impact this has on families
  - needs in terms of ethnicity, diversity, religion and culture
  - examples of good policy and practice whereby children and adult services have a joined-up approach, other departments (e.g. Housing and Education) are involved, and where the views of service-users have been included in the development, planning and delivery of services
- The final product will be in the form of a resource guide containing: a template for a working protocol between adult and children's services; a protocol to use as an

example; and various other resources, case and practice examples and links to other websites. This should be available by the end of 2006.

- An easy read version may be produced.
- The work has been undertaken with close links with the Norah Fry Research Centre that is simultaneously conducting work on parents with a learning disability.

### National Centres for Independent Living (NCIL)

Project Number: 11
Title: Wider Option. Report of a research project into intensive support schemes for direct payments
Dates: Completed (published 2005)
Organisation: National Centre for Independent Living (see http://www.ncil.org.uk )

Summary:

- This is a report of a research project into Intensive Support Schemes for direct payments.
- The report highlights some of the different intensive support scheme services provided across the country and the factors that have influenced their provision.
- It looks at low take up of direct payments by different groups of disabled people and some of the more intensive direct payments support service options available.
- It considers the support schemes' effectiveness in supporting independent living and implications for policy and practice.

Relevant results:

- Types of support schemes include Independent Living Trusts, Third Party Payments, Brokering and User-controlled Personal Assistance Agencies.
- One of the main problems with implementing Intensive Support Schemes is the lack of easily accessible information for advisors and for individuals contemplating Direct Payments.

Recommendations:

- Clear, accessible guidance and practical resources should be made available as a matter of priority to support people in understanding Intensive Support Schemes and their role.

### Commission for Social Care Inspection (CSCI)

Project Number: 12
Title: CSCI Information Sources Market Research Presentation
Dates: May 2005
Organisation: Continental Research (Commissioned by CSCI)

Summary:

- The CSCI commissioned this research to gain a full understanding of current/potential clients': media consumption; access to and usage of communications, e.g. mobile phones, Internet; awareness and knowledge of CSCI; and satisfaction with information available on care services.
- The research focussed on information about care homes.
- The researchers interviewed elderly people living at home with care, living in a care home, or considering a care home; adults with physical or learning difficulties living at home with care or living in a care home; and the adult relatives of each group.
- Relatives, friends, social services and care workers were main sources of information. People in care homes tended to rely more on friends and relatives; those cared for at home, on social workers and care managers. Relatives tended also to ask GPs or nurses for information.
- A sizeable minority of the elderly either thought it difficult or were unsure how easy it would be to source information on care homes. Higher dissatisfaction was expressed by the relatives. All would benefit from better 'sign posting' of official sources to use and procedures to follow.
- The main areas of criticism about the ease of obtaining information on care homes for the elderly concerned the lack of support people were given finding suitable a home. There was also some concern about the quality of homes generally.
- A significant minority of adults with physical or learning difficulties were unsure or dissatisfied with the ease of obtaining care information. This was especially apparent amongst the relatives of those receiving care at home.
- Awareness of literature about care for adults with physical or learning difficulties was higher among relatives than users.
- Large type, an easy to read style and video were formats welcomed by all care users. Eighty per cent of relatives of people with physical/learning difficulties were happy with regular print. Relatives of the elderly wanted more visual formats.
- The presentation reported percentages of all care users and relatives using mobile phones, the internet, the types of television programmes watched and radio programmes listened to, and newspaper and magazine readership.

# Summary details of development projects/other initiatives to improve access to information

## Department of Health

### Recently completed

*Section 64 grants*

Project Number: 13
Title: DIAL Raising Quality and Achieving Accreditation project
Dates: 2002-2005
Organisation: DIAL UK (Section 64 grant)

Summary:

- The project aims to support local DIAL advice centres to achieve the new DIAL UK Quality Standards.
- The project will provide practical targeted development support to DIALs to assist them to provide high quality advice and information to the 250,000 disabled people using their services each year.

Evaluation of project:

- It will provide an auditing process to accredit the quality of their services.

Project Number: 14
Title: Disabled Parents Rights Handbook Project
Dates: 2001-2005
Organisation: Disabled Parents Network (Section 64 grant)

Summary:

- The project is to research, produce, launch and distribute a handbook that will inform disabled parents of their legal rights and entitlement to social and health services.

Evaluation of project:

- None known.

Project Number: 15
Title: Health and Social Welfare Project (Community Care)
Dates: 2002-2005
Organisation: The Disability Law Service (Section 64 grant)

Summary:

- The project will increase the capacity of the voluntary organisation’s health and social welfare project in the area of community care by extending their advice and casework hours.
- The Disability Law Service will be able to assist more disabled adults and children seeking advice and support in accessing services from their local Health Authority and/or social services.
- It will also be able to offer support to other organisations providing information and advice for disabled people.

Evaluation of project:

- None known.

Project Number: 16
Title: Website Information project
Dates: 2002-2005
Organisation: Disability Alliance (Section 64 grant)

Summary:

- The Disability Alliance website information project will provide a unique, on-line, expert resource on social security and other benefits and services for disabled people.
- The project will help improve the quality of the service provided by local advice agencies to their disabled customers.
- It will also promote independence by providing disabled people with access to information so that they can make informed choices.

Evaluation of project:

- None known.

Project Number: 17
Title: Which Powered Wheelchair project
Dates: 2003-2005
Organisation: Research Institute for Consumer Affairs (RICA) (Section 64 grant)

Summary:

- The project is a partnership initiative by Ricability and the consortium Empower, to develop and publish a unique interactive guide for consumers choosing a powered wheelchair, scooter or buggy.

Evaluation of project:

- None known.

**Current**

Project Number: 18
Title: English DSDC (Dementia Services Development Centre) Web project
Dates: 2004-2006
Organisation: Dementia Voice (Section 64 grant)

Summary:

- The project will produce a website with information about the English Dementia Services Development Centres, providing open access to a database with information about services for people with dementia.

Evaluation of project:

- None known.

Project Number: 19
Title: Elders Project
Dates: 2005-2007
Organisation: RESPOND (Section 64 grant)

Summary:

- People with learning disabilities are living longer.
- Living longer means they are more likely to experience bereavements, become aware of their own mortality and have an increased risk of developing dementia, and to experience anxiety as a result.
- This project will be the first to provide a dedicated helpline for older people with learning disabilities and the staff and families supporting them.
- In addition it will provide the following services:
  - loss education groups for older people with learning disabilities and the staff and families supporting them;
  - training for staff on practical loss strategies and aiding service planning;
  - bereavement therapy for people with learning disabilities.

Evaluation of project:

- None known.

Project Number: 20
Title: Epilepsy Information Network
Dates: 2003-2006
Organisation: National Society for Epilepsy (Section 64 grant)

Summary:

- It aims to meet the information needs of people with epilepsy and their carers, by providing information on issues including explanations of diagnosis and treatment, minimising risk and maximising independence.
- It provides epilepsy information through epilepsy information services in neurology and paediatric outpatient departments and other healthcare settings, such as community clinics, health centres and healthy living centres, as well as a few residential settings for people with learning disabilities.
- The service uses various methods of delivering information to the wider community including information stands in shopping centres and libraries, and through volunteers giving presentations to schools to help raise awareness of epilepsy.
- The EIN has produced the following tools:
  - training programmes for volunteers working in medical settings;
  - training for volunteers in presentation skills;
  - policies and procedures for volunteers;
  - Schools Awareness Programme.

Evaluation of project:

- None known.

Project Number: 21
Title: Eye POD/National Eye Clinic Support project
Dates: 2006-2009
Organisation: Action for Blind People (Section 64 grant)

Summary:

- One of the core objectives of this project is to establish professional high quality eye clinic based information and support services for visually impaired people through out the UK.
- The Eye POD project aims to provide equitable and timely access to high quality information and support based on the needs of the individual, thus empowering the individual to exercise choice, control and access the interventions which promote self care and independence.
- The Project has a strategic aim of developing pathways for liaison between PCT’s, NHS trusts, statutory services, eye professionals and the voluntary sector.
- The project team are working strategically with a number of other voluntary sector organisations and representatives for the Royal College of Ophthalmologists and the Eye Care Pathways Steering Group to identify the gaps, highlight examples of

best practice and develop a set of toolkits to facilitate providers in improving the quality of their services.

Evaluation of project:

- None known.

Project Number: 22
Title: Health Information Project
Dates: 2005-2008
Organisation: Spinal Injuries Association (SIA) (Section 64 grant)

Summary:

- People with spinal cord injury (SCI) are confused or ill-informed over health issues and this can have a profound effect on their ability to lead an independent and fulfilling life.
- Many people with SCI confess to not understanding the terminology of health professionals, or have only received a partial education on the physical aspects of managing their condition, particularly when they have not been treated in a specialist Spinal Injuries Centre.
- This project aims to overcome this issue by developing a unique support service that will enable people with SCI access to support, information and advice on improving their health and living independently.

Evaluation of project:

- None known.

Project Number: 23
Title: House Adaptation Advisory Service (HAAS) project
Dates: 2003-2006
Organisation: The Centre for Accessible Environments (CAE) (Section 64 grant)

Summary:

- This project will compile a register of architects, surveyors and consultant occupational therapists, based throughout the UK, who have demonstrable knowledge of the housing needs of disabled and older people, and to whom CAE can with confidence refer the steady stream of enquiries who seek local, informed advice on house adaptations and related issues.

Evaluation of project:

- None known.

Project Number: 24
Title: Localised Country-Wide Database Project
Dates: 2004-2007
Organisation: StartHere www.starthere.org (Section 64 grant)

Summary:

- StartHere is a one-stop electronic information service whose mission is to connect people in need to available help and resources – at the touch of a button.
- It is a community information service meeting the needs of people with illness and disabilities, older people and their carers.
- The aim of this project is to build a unique fully integrated database that connects people to statutory and voluntary sources of help and support both nationally and locally across the country.

Evaluation of project:

- None known.

Project Number: 25
Title: My Pregnancy, My Choices
Dates: Planned for 2005-2007, but start date delayed
Organisation: Change (Section 64 grant)

Summary:

- To produce a book for parents with learning disabilities to help them access to all info they need to be able to make informed choices and use mainstream services.
- This book will be a follow-up to ‘You and your baby 0-1 year book’, an accessible guide for parents with a learning disability, parents who cannot read or write very well and parents whose first language is not English. ‘You and your baby’ is available as a book or CD.

Evaluation of project:

- None known.

Project Number: 26
Title: National Information Resource of Assistive Technologies for People with Dementia
Dates: 2005-2008
Organisation: Trent Dementia Services Centre (Section 64 grant)

Summary:

- To meet the need for a central, free, reliable, up-to-date information resource on assistive technology (AT) devices that specifically promote the safety and independence of people with dementia and memory impairments in their own homes, and is accessible by carers, people with dementia and professionals.

- The project will create a user-friendly national web-based database providing current information on existing AT devices; their function, cost and availability.
- It will also develop educative information for professionals on the role of AT in person centred needs assessment and care planning for people with dementia.

Evaluation of project:

- None known.

Project Number: 27
Title: Technology Advisory Project
Dates: 2005-2008
Organisation: SENSE, the National Deafblind & Rubella Association (Section 64 grant)

Summary:

- The aim is to recruit a Technology Advisor to consult deafblind people, collate and disseminate information on technology for deafblind people, train and advise community based workers, and work with researchers and manufacturers developing accessible technology for deafblind people.
- There will be a catalogue and website on aids and equipment.
- Advice and information would be disseminated via exhibitions.
- It is hoped that direct support will be provided to deafblind people, families and/or carers via health and social care professionals in local authorities and voluntary agencies.

Evaluation of project:

- None known.

Project Number: 28
Title: Understanding Community Care Charges
Dates: 2005-2006
Organisation: Disability Alliance (Section 64 grant)

Summary:

- Community care services can help many disabled and elderly people to live independently, but the fear of the cost of services can be a barrier to access, especially if people do not understand how the charging system works.
- Disability Alliance propose to produce a user-friendly guide which will provide a summary of the legal position on charging for community care services and will also explain Direct Payments and the role of the Independent Living Fund.
- The guide will be used by disabled and older people and their carers and also by local authority staff and advisers in local agencies.

Evaluation of project:

- None known.

*Other DH projects*

Project Number: 29
Title: Information Access Project – Providing information to people with neurological and other long-term conditions
Dates: 2004-2006
Organisation: Brain and Spine Foundation, in collaboration with the Neurological Alliance and the Long-term Medical Conditions Alliance

Summary:

- Builds on Information Impact Project which is investigating how correct management at primary care level and a patient’s ability to access appropriate information, following diagnosis, influences patient outcomes.
- Information Access Project includes both health and social care and aims to:
    - improve access to information by assisting health, social care and other providers to implement evidence-based standards of good practice in information and advice;
    - support individuals in accessing information directly;
    - support providers to provide an effective information service by producing a toolkit and protocols for an Information Standard, identifying workable models of good practice (to ensure patient involvement and partnership in the process of defining information needs and accessing information and for professionals involved in providing information).

Evaluation of project:

- None known.

Project Number: 30
Title: One Stop Shop for Care Home Advice for Older People
Dates: Current, for 6 months
Organisation: Elderly Accommodation Council

Summary:

- Project in response to the OFT report ‘Care homes for older people in the UK’.
- Project is funded by HSBC but being overseen by the DH.
- The project will develop a web-based one stop shop for care home advice. There will also be a face to face version so that people who prefer talking one to one can do so.
- Advice will be provided about care homes and supported housing. There will be links to inspection reports but also ‘softer’ information such as details of activities available in care homes.

Evaluation of project:

- None known.

Project Number: 31
Title: Partnerships for Older People Projects (POPPs)
Dates: Ongoing
Organisation: Local and national evaluations

Summary:

- Partnerships for Older People Projects are about developing radical new approaches to the way in which services for older people are delivered. The pilots are being evaluated nationally and locally. Some examples of POPP initiatives that are aiming to improve access to and availability of information include the following:
- Networker programme (Camden). Networkers are older volunteers who pass information by word of mouth creating a ‘network’ of information. They also provide some practical help (e.g. making phone calls to people with memory problems to remind about hospital appointments and medication)
- Way-finders initiative (Dorset) – This initiative will identify and recruit local older people, in partnership with voluntary organisations, to be local ‘advocacy workers’ supported by local leaders. Their role will include raising awareness of service availability, making information accessible on a range of levels, and identifying support and help within communities for older people being discharged from hospital and other institutional care such as prisons. Way-finders will use information that is available from local voluntary and statutory agencies and have access to more specialised information on complex issues.
- Webmaster development post (Knowlsey) - The project includes the establishment within Age Concern Knowsley of an information/webmaster development post to collate and maintain information, including community resources, which will be publicly available. Information services will be developed, which can be accessed through a variety of methods, such as the internet, booklets, one stop shops and specialist advisory services, that provide information to people in their own homes.
- Gateway Team (Manchester) - The Gateway team will provide a high profile, single point of access for older people and staff. Offering support and a navigation role, the team will operate a telephone service and an outreach facility. The Gateway will link together existing services, including Supporting People, the Pension Service through the Link-Age service, Carers’ groups, and mainstream Council and community groups. The service will be underpinned by shared referral and contact protocols developed alongside the Single Assessment Process, and a comprehensive electronic database of community information.
- Voluntary, Community and Faith Sector Sign Posting Service (Sheffield): Amongst other things, this project will provide detailed information about which voluntary, community and faith sector organisation is providing what service to whom; establish a postcode database to instantly identify services in any given area and produce a website providing news bulletins, facilitated discussion forums, links to helpful organisations.

Evaluation of project:

- There is a national evaluation of POPPs. The specific aims with respect to access to information are not known.

Project Number: 32
Title: SWISH – Smarter Working in Social Care and Health
Dates: 2005-2006
Organisation: Centre for Aging Population Studies

Summary:

- The project aims to improve older people's and carers' access to appropriate information and services; enrich health and social care databases; and profile local populations by using an integrated expert system to identify health risks and status.
- This project is using an 'expert system' called the Health Risk Appraisal for Older People (HRAO) which ahs been tested in a pilot in three European countries. The system consists of a self-administered questionnaire to identify risk factors. Based on the results of the questionnaire, the system produces specific personalised advice on how to change health risk behaviours and thus the delivery of targeted and personalised advice and information.
- New sections, for example on housing need, are being developed.

Evaluation of project:

- Changes in health behaviour and risks are being measured through two cycles of the questionnaire. Older people are also taking part in focus groups to explore perceptions of the value, usability and appropriateness of the information given to them through HRAO.
- Amongst other things, the project is beginning to demonstrate that the HRAO allows the delivery of targeted and personalised advice and information that allows older people to take action to change their health risks.

Project Number: 33
Title: Valuing People Support Team
Dates: Ongoing
Organisation: Part of the Care Improvement Services Partnership (CSIP)

Summary:

- The Valuing People Support Team is responsible for implementing the 2001 cross-government white paper, Valuing People, which sets out plans for making the lives of people with learning disabilities and their families better. The team has a representative in each region in England to help local authorities are implementing Valuing People (VP).

- VPST are working on five key themes – people and families having a voice; employment; access to mainstream health; bringing people back home from out of area placements; and self-directed support (e.g. In Control pilots, individual budgets).
- A small grant of £5000 has been given to nine advocacy organisations around the country, one in each region. This money will be used to help them get training about making information more accessible and to think about marketing a business to make information accessible. The idea is that this should be done by people with LD rather than professionals, as those with LDs know what the issues are.
- VP has a website about easily accessible information (www.easyinfo.org). It is a website about making information easier for people with learning difficulties, about bringing people together, finding out about good ways of working and sharing ideas. There are sections including guides on making information easier, tools for helping make information easier, showcase examples and current research.

Evaluation of project:

- None known about use of £5,000 grants or effectiveness of www.easyinfo.org.

**Planned/proposed**

Project Number: 34
Title: Carer's HelpLine
Dates: Planned
Organisation: DH

Summary:

- In the White Paper Our Health, Our Care, Our Say, the government has committed to establish an information service/helpline for carers. The helpline will offer information in the widest sense – from legal entitlements to contact numbers for support groups to advice on benefits.

Evaluation of project:

- None known.

Project Number: 35
Title: Health Search Engine
Dates: Currently in the planning stages
Organisation: DH

Summary:

- To develop a search engine that aids quality assurance by linking to the information accreditation scheme.
- Through signposting, to assist people in finding good quality information that is relevant to them.

Evaluation of project:

- None known.

Project Number: 36
Title: Information Accreditation Scheme
Dates: Scheme to be implemented by the end of 2007
Organisation: DH

Summary:

- To improve the quality of information on health and social care.
- To accredit information providers who reach minimum standards.
- Accredited providers to display a visible quality ‘kite mark’ that is recognisable to users.

[See ‘Quality of health information for patients and public’ by Picker Institute in current projects on investigating access to information.]

Evaluation of project:

- None known.

Project Number: 37
Title: Information Prescription Project
Dates: In the early planning stages
Organisation: DH

Summary:

- To develop an information prescription, that health or social care professionals can provide to people newly diagnosed with a long term condition or disability.

Evaluation of project:

The project will test:

- A paper information prescription pad that would be pre-populated with sources of information on, for example, benefits, NHS Direct, nhs.uk, social care websites.
- A technical infrastructure that will enable personalised and local information, for example about home care services, to be extracted from a database and presented to people.

Project Number: 38
Title: National Library for Health for Specialist Libraries Information Support - Neurology
Dates: 2006 - 2008
Organisation: NHS Connecting for Health

Summary:

- To produce a neurology specialist branch for the National Electronic Library for Health (NeLH) to enable health and social care professionals to access high quality information about long-term neurological conditions through web-based portal.
- To make sure information on long-term neurological conditions by NHS Direct and NHS Direct Online is up to date.
- NHS Direct will provide links to a web-based service giving access to recognised sources of high quality information designed for use by people with long-term neurological conditions, their families and carers and members of the public.

Evaluation of project:

- None known.

| | |
|---|---|
| Project Number: | 39 |
| Title: | Community Information Bank |
| Dates: | To begin mid-2006 |
| Organisation: | DH |

Summary:

- To work with PCTs, local authorities or others to investigate how an integrated database about services can be developed and kept up to date.
- To develop a database(s) that will be used to provide locally based information, for example about support groups or care homes, to helplines and other information providers.
- This project supports recommendations for community navigators in Better Information, Better Choice, Better Health and Our Health, Our Care, Our Say. The database needs to be in place for the information prescription to work.

Evaluation of project:

- Methods of keeping the database up-to-date will be tested.

| | |
|---|---|
| Project Number: | 40 |
| Title: | Social Care Link |
| Dates: | Proposed but not yet in the planning stages |
| Organisation: | Proposed in the DH White Paper, Our Health, Our Care, Our Say |

Summary:

- The proposal is that every LA should have a detailed directory of information about services, integrated with health.

Evaluation of project:

- None known.

## Office of the Deputy Prime Minister (now Department of Communities and Local Government)

### Recently completed

None identified.

### Current

Project Number: 41
Title: Directory of Supporting People Services
Dates: Ongoing, recently established
Organisation: ODPM (now DCLG)

Summary:

- Supporting People offers vulnerable people housing-related support that complements existing services.
- It provides housing related support to prevent problems that can often lead to hospitalisation, institutional care or homelessness and can help the smooth transition to independent living for those leaving an institutionalised environment.
- Services can be long or short term and include accessing a community service alarm, a home visit for a short period each week or an on-site full-time support worker for a long period of time.
- A new online directory of services has recently gone live.
- It includes all the services that Supporting People fund.
- Information on client groups and services has come from local authorities.
- Users as well as care managers/other intermediaries making referrals should find the directory useful.
- Its public availability empowers people to make choices.
- More integration with other care support would be advantageous.
- Leaflets advertising the directory have been sent to libraries and GP practices.

Evaluation of project:

- The project team are investigating how the directory can be improved using web feedback and regional preview events.
- Work is ongoing to improve the usability of the software, the quality of data, to refine the validation rules for the submissions from LAs, and to keep the details up to date.

Project Number: 42
Title: E-citizen Factsheet Project
Dates: Ongoing
Organisation: Oldham Metropolitan Borough Council

Summary:

- Oldham Council developed web-based fact sheets for its services following an audit in 2003 that showed paper leaflets were out of date, poorly presented and of unknown use. They were produced also in response to instruction from DH standards that asked for accessible information to be produced.
- Oldham Council's web-based fact sheets were marketed in Oldham as a pilot by the E-Citizen project. ODPM (now DCLG) funds the E-Citizen project which conducts market research and tests marketing communication campaigns in order to raise awareness and drive take-up of local authority e-channels.
- There are 138 fact sheets covering adult and children's social services. The fact sheets are in 14 font plain English, many being produced with explanatory pictures. Each sheet is coded and linked to categories of council services provided. The number of downloads, page views, user sessions and unique users can be monitored.
- The E-Citizen pilot was so successful that the fact sheets are now being rolled out throughout England. In April 2006, all councils will be sent from ODPM (now DCLG) a resource pack including 221 fact sheet templates (covering mainly social services information but environmental as well) and a handbook for staff on how to write, code and monitor the fact sheets together with all the marketing communications artwork for councils to use if they wish to advertise the fact sheets in their area.

Evaluation of project:

- None known.

Project Number: 43
Title: Local Directgov Programme - Connecting Local Authorities to Directgov
Dates: Ongoing
Organisation: ODPM (now DCLG) (see www.localegov.gov.uk )

Summary:

- A programme that will improve accessibility to public services via the internet by linking together Directgov and Local Authority online services into a single offering.
- It will offer automatic deep linking straight to a Local Authority service or interaction page rather than just a home page.
- There is research generally that people want to know what the access/contact point is locally for services such as, for example, housing adaptations.

- The benefit of deep linking Directgov to Local Authority services and interactions is that the user only has to learn how to navigate one website. It means that they will be able to find the service they want online, without having to know which government department or section delivers it, or even which Local Authority is responsible for it in their location.
- Local Directgov Programme system linking to Local Authority websites will go live in January 2006 with links to a prioritised set of Local Authority services and interactions.
- Local egov will provide the tools, help and knowledge to ensure that these links can be effectively maintained for the future, within a Local Authority’s own IT department.

Evaluation of project:

- None known.

### Planned/proposed

None identified.

## Department for Work and Pensions

### Current

Project Number: 44
Title: Directgov website – over 50s section
Dates: Ongoing
Organisation: DWP

Summary:

- The over 50s section of the Directgov website covers all older people’s issues across government. It is not confined to one topic area.
- The target audience ranges from healthy, affluent people in their 50s to very frail elderly people. It is for the latter group that information about social care, care homes and maintaining independence is most relevant.
- In developing the over 50s section, the DWP with the DH researched the types of information that would help people to maintain independence where possible, and where not possible, to be able to make choices about their support.
- Where relevant and available, local authority web pages can be accessed directly from the Directgov pages. This initiative has been part of the ODPM (now DCLG) project through its ‘home and communities’ section to ‘deep link’ local information (see ODPM Local Directgov section).

Evaluation of project:

- Information on the site is arranged in categories such as working, learning, health and well-being. Within each of these are further subgroups of information. The new format was launched in January after consultation to see what information people wanted delivered and how, and is about to be evaluated now that it is live. This post-launch evaluation will ask people, amongst other things, about the subject areas, the categories in which information can be found and the usefulness of the information.
- The Directgov website in its entirety is constantly monitored and its use evaluated by the Cabinet Office.

**Planned/proposed**

| | |
|---|---|
| Project Number: | 45 |
| Title: | Link Age Plus |
| Dates: | to begin 2006 |
| Organisation: | DWP |

Summary:

- LinkAge Plus will entail a programme of pilots that will fully integrate services for older people (the working assumption for the definition of older people has been over 50s) and would be designed to meet the needs of each local area, whilst conforming to a set of agreed principles.
- The objectives of the programmes are:
    - To build a robust evidence base to support the case for joined up services in terms of delivering better outcomes for older people;
    - To build an evidence base that supports the economic case for fully joined up/holistic services for older people;
    - To test the limits of holistic working and;
    - To build a body of good practice and lessons learned for other partnerships and communities so as to encourage wider application of the approach, beyond pilot sites.
- Up to eight Link Age Plus pilots will be selected by the end of April 2006. Pilots will run for two years.
- Local authorities will be the lead partners in the pilots, but will be expected to work with voluntary and community organisations, and other central and local government departments.
- Pilots will develop local models for joining up services for older people that are wider than just health and social care. As a minimum the basic LinkAge Plus model should include:
    - Social care
    - Health services
    - Pensions/benefits

  - Housing
  - Local voluntary sector organisations
  - Holistic approach to housing-home safety and improvement
  - Fire, police and neighbourhood wardens
  - Transport
  - Access to information about employment – new roles or continuing in current work
  - Adult education
  - Leisure services
  - Advocacy – need to give independent information
  - Volunteering

Evaluation of project:

- There will be both local and national evaluation of models.

## Independent organisations

### Disabled Living Foundation

| | |
|---|---|
| Project Number: | 46 |
| Title: | SARA self assessment tool |
| Dates: | Ongoing |
| Organisation: | Disabled Living Foundation |

Summary:

- To develop a web-based self assessment tool to help people assess their low level equipment needs.
- SARA is backed up by the DLF's database of equipment information, DLFDATA, and recommends equipment drawn from approximately 140 categories comprised of approximately 1900 products.

Evaluation of project:

- SARA was piloted originally through the DH ICES (Integrated Community Equipment Stores) project with the DLF as a partner. It was accessed via kiosks in equipment centres and pharmacies.
- At the end of that pilot, the DH licensed the DLF to develop the tool further and provided some funding to help develop a web-based version. DLF is now working with new partners to further develop the web version. The current web version was launched in January 2006.

**Commission for Social Care Inspection (CSCI)**

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|---|---|
| Project Number: | 47 |
| Title: | Social Care – Choosing The Right Service For You |
| Dates: | April 2006 |
| Organisation: | CSCI |

Summary:

- This is a new guide that gives people advice and information about choosing the right social care for them. The guide is designed to fill the gap in good quality information available to people looking for or using care services.
- The guide was developed as a result of research by the Office of Fair Trading and CSCI. Both found that access to this kind of information varies a lot across the country.
- The new guide encourages people to ask the right questions when looking for care and to say no if they are unhappy with what is being offered.
- Every council in England will receive copies of the guide so they can give them to people who are looking for care services. The guide will also be available on CSCI's website and in alternative formats for disabled people and different languages for people who don't read English.

Evaluation of project:

- The content of the guide was developed with the help of people who use services, councils, and social care professionals. The draft guide was examined in three local authorities and by two separate user groups.
- Evaluation of the guide will include analysis of the take up of different formats.

# Appendix 8 List of relevant articles identified in the literature searches

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Wates, M. (2003) *It Shouldn't be Down to Luck: Results of a DPN consultation with disabled parents on access to information and services to support parenting*, London: Disabled Parents Network (DPN).