WHAT OLDER PEOPLE SAY ABOUT CARE SERVICES:

A literature review for the King's Fund Care Services Inquiry

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SUMMARY OF KEY POINTS

A quality service
The literature is generally consistent about how older people describe good quality care services. The following key features are mentioned frequently.

Independence
Independence is valued highly by older people and the desire to remain independent for as long as possible is often expressed strongly. Independence means different things to different people, and in different settings, but most commonly older people talk about independence in terms of staying in their own homes and avoiding residential care.

Having support to remain in their homes and help to maintain their home environment, therefore, is considered essential by older people to enable their independence. In addition the following are all strongly associated with independence:

- autonomy – being able to decide things for yourself
- having enough money
- being reasonably healthy - both physically and mentally
- not being a burden
- access to affordable and suitably adapted transport
- access to information.

Social life
Older people living in all settings value being part of social networks. The extent to which care services facilitate social interaction is often seen by older people as a measure of their effectiveness. For those living in residential care the company of other residents is frequently prized above other factors. Older people living in their own homes often stress the social value of home care services and some studies find the quality of the social interaction between care providers and those living alone is equally, and sometimes more, important as the care tasks undertaken.

Responding to individual needs
Services which are capable of responding to individual need are highly valued. In order for independence not to be compromised, services need to be adaptable as needs change. Older people require care packages that enable support for low level needs, such as assistance with cleaning and shopping, before they are more dependent and have high care needs. This requires sensitive, consistent and ongoing assessment processes to be in place.

The ability to respond to individual needs, such as language spoken or diet, is particularly important to some Black and minority ethnic (BME) older people. For some having a choice of provider is valued as a way of achieving access to appropriate services, for instance day care services with Halal or Chinese food.

Flexibility, choice and control
For many older people being able to have choice and control over their care is more important than choice over which agency provides it. Control, and consistency, over the timing of meals, bathing and other personal care is essential for people to manage their daily lives. On the whole older people want to be cared for by regular carers who become familiar with their particular needs and preferences, and with whom they can build up a relationship.

Communication

The extent to which older people are involved in decisions about their care, and listened to by care staff and providers, is an important measure of quality. Communication with care staff is important to older people both for the information that is conveyed and for the quality of the relationship between the person and their paid carer. Older people want to have communication on the tasks to be carried out and issues that are troubling them. They also want to have day to day things explained to them, for instance the change from their shopping or how to fill in a form. Older people often construe the lack of communication from some paid carers as a lack of respect. A basic quality issue for some BME service users, and their informal carers, is that care workers are able to speak their own language in order to communicate effectively.

Adequately trained staff

Older people want to be sure that those who are caring for them have appropriate training. They are particularly concerned about safety. There is some literature to suggest that older people would prefer a focus on communication, language skills and customer care – being friendly and obliging, having a positive attitude – rather than training focused on performing functional tasks.

Fears and concerns of older people

Some themes reoccur throughout the literature as major preoccupations and issues for older people.

Concerns about affordability

There is a considerable amount of material in the literature about the concerns of older people on the issue of paying for care services, and the impact this may have on access to suitable services. Older people want to be economically independent and, on the whole, do not oppose the principle of contributing to their own care costs, but many have concerns about the level of costs and the perceived inconsistencies within and between charging policies.

This is increasingly a concern as people commonly live 25 –30 years following retirement. Levels of dependency and frailty tend to increase with age, leading to higher levels of need and higher care costs. People fear that the money will run out at the time when they may need it most. There is also a sense of injustice and lack of fairness as older people feel they are having to pay twice for their care (through tax and National Insurance and then again as users of services). Those who have worked part-time or been on low or insecure incomes are particularly concerned about having enough money to fund increasing care needs as they get older. This particularly impacts on women and BME older people. There is also a sense of injustice at what is perceived to be the penalty on thrift – people who have savings and assets have to contribute most.

Concern is expressed about the inequalities in benefits and concessions provided to older people between different authorities. Charging may result in people refusing help or not accessing services such as day care. Charging for day care has particularly adverse effects for some BME people for whom the community centre may be the sole contact.

There is a lack of clarity in the information older people are given about charging policies. Studies suggest that older people find it hard to understand rules about charging. Some older people fear accessing the home care service in case their benefits or other services are

affected. Some find it difficult to understand how direct payments affect other benefits that they receive.

Ageism

There is concern amongst older people that the distribution of resources is unfair and ageist and there are references to ageism and age discrimination throughout the literature. Older people experience ageism when trying to access services and whilst using them. Reports of staff being patronising and older people feeling that they are treated with a lack of dignity are common. Specifically, older people experience age discrimination when crossing the social services administrative boundary between 'adult' and 'older persons' services.

Change and lack of continuity

Older people fear unnecessary change and prefer to be in familiar surroundings with familiar and regular care staff. They generally want to stay living in their own homes, where they may have lived for most of their lives, and where they have their own furnishings and belongings. When they do have to move, for instance from their home to a care home or sheltered housing, they are very reluctant to move again.

Independence

Older people often fear losing independence above all, though the desire to stay living independently in their own homes can lead to social isolation.

Complaining

Although older people express considerable dissatisfaction with their care – home care in particular – they are often reluctant to formally complain. The literature suggests that many older people do not know how to make a formal complaint, but more importantly, even when they do, they are very reluctant to complain due to fears about the impact on their receipt of services and a lack of confidence.

Older people's experiences of care

Home care

Home care services often do not meet the needs of individuals and older people express considerable dissatisfaction with various aspects. A predominant issue is the lack of access to low level care and assistance such as help with cooking, cleaning, shopping, gardening and routine maintenance. Shortcomings are generally caused by a combination of poor and patchy assessments that do not take account of individual needs and the quality of the staff who deliver the care. Some people report very good experiences with particular individual care staff who are more flexible, "obliging" and good company, but on the whole there is concern that care staff are non communicative, turn up late, do not stay for the time allotted and are inflexible about the tasks they undertake.

Home delivery meals services are also criticised, most particularly by BME older people, as they often fail to cater for specific cultural needs.

Day care

Day care is often viewed positively by older people and their carers, though some people with dementia found it an "ordeal". For older people themselves the opportunity to get out of the house and meet others is welcomed as are some of the activities. Organised outings are often

particularly mentioned as positive aspects of day care. For carers, day care is welcomed as respite.

Older people often experience problems accessing day care, however. This is firstly, because there is not sufficient provision, especially for particular groups such as some BME communities, people with mental health problems and those with other special needs. Secondly, there is a lack of reliable and suitable transport.

Sheltered housing

Older people regard sheltered housing as a way of feeling secure, while retaining as much independence as possible. It is usually seen as a preferable alternative to residential care. The social aspects are valued - residents value having their own rooms but also speak positively of shared spaces (for example living room and dining room). Having the freedom to come and go is also valued. Older people in sheltered housing like to feel part of the wider community and have access to local facilities.

Problems noted about sheltered housing include the lack of 24 hour support from wardens in some facilities.

There is also a problem about awareness of this kind of facility as an option for older people. Lack of awareness is particularly common amongst BME communities.

Residential care

On the whole, older people fear residential care and are reluctant to go into a care home. Most do not choose to go into residential care, but the move is often forced on them by circumstances and their increased frailty. The actual experiences of older people in residential care, however, sometimes exceed expectations and having company, in particular, is valued by many. Others value the freedom of being relieved from daily tasks of cooking and shopping. Older people often find a way of maintaining some independence within the constraints of a care home.

Areas of dissatisfaction with residential care are often similar to those with home care – the lack of staff who spend time and communicate with older people; the lack of control over timing of meals, baths and bedtimes; and the lack of individual stimulation.

Information and advocacy

There is no shortage of information, but older people often experience problems in accessing the information they need. The volume of information available can be as problematic as an absence of information particularly if the information is not targeted at older people specifically, or available in the places they would be likely to access it. There is a need for a variety of formats to meet different needs and disabilities, and for both culturally specific and translated information.

Older people value information that is topic-based, rather than the agency-based information that is more frequently offered. They want timely information, often at a point of change or crisis in their lives, and comprehensive information actively offered in their first language at such stages.

Older people do not generally find distinctions between information, advice and advocacy meaningful. Older people often do not know what questions to ask to elicit the information

they need and they welcome advice that helps relate information to their particular circumstances. They also welcome assistance to obtain the services they need.

Dementia

The experiences of older people with dementia are often, but not always, expressed through their carers. The overall picture is that the needs of people with dementia are poorly catered for in all care settings. There is a need for specific and focused service provision for this increasingly large proportion of older people.

Black and minority ethnic older people

There is a predominance in the literature of studies that wholly or partly focus on the needs and experiences of BME older people. It is of concern that these studies and reports tend to focus on the same areas of concern and repeat the same recommendations over the five year period under review. There appears to be little learning from the studies and even less action to remedy the problems identified. Some very basic, but essential, issues are consistently raised, such as care workers being able to communicate with service users.

On the whole, the needs of BME older people are not significantly different from older people generally, though some of the problems experienced impact more harshly on some BME older people because of poverty, isolation, racist assumptions and a failure to meet individual needs. If services for older people were able to meet the individual needs of older people generally, a large proportion of the issues that BME older people have would be addressed.

What older people want

Older people want services that support them to be independent, and that meet their individual and expressed needs. The distinction made between personal care and other kinds of support are not always meaningful to older people. Often they want assistance with practical tasks, such as cleaning and gardening, help with maintaining independence and social lives as well, or instead of, help with personal and bodily care, such as bathing or dressing.

Older people want to be part of social networks, whether they live at home, in sheltered housing or in residential care. They want more control over their daily lives when they are using care services and for their preferences to be recognised. Older people want information and advice services that actively help them to exercise control and choice through advocacy and support.

Conclusion

Older people expect to be treated as individuals, having their particular needs met and their preferences respected in order to support their autonomy. The importance of social interaction and mental stimulation is paramount for many older people.

Provision for older people should be primarily focused on promoting an approach to integrated services that enable people to receive the physical support and care they need whilst also promoting opportunities for social integration with other people. This should be a priority for those designing care services, housing and support with, and for, older people.

INTRODUCTION

This literature review was commissioned as part of the King's Fund Care Services Inquiry to examine what older Londoners and their carers have been saying about care services in recent years. The King's Fund Committee of Inquiry also commissioned several other pieces of work to find out about the operation of care markets in London, the quality of care services, and new developments in care services that are offering an alternative to traditional care services. The views and experiences of older people are integral to the King's Fund's Inquiry, but that begs the question of how best to seek the views of older people and their carers. While views have been sought directly in a number of ways by the Committee of Inquiry and its researchers, it was also felt that much can be learned about what older people and their carers have said from research and consultation conducted recently. Our brief was to review the literature that records this work, so that it is fully taken into account and the voices of older people are not overlooked.

We were asked to look at what older people wanted from care services, how easy it has been to find and choose care and support that suits them and how satisfactory the services they use are. It was expected that this would entail reviewing relevant reports, including those arising from surveys and consultations undertaken by local authorities and NHS bodies, voluntary organisations and inspectors. We found material in all of those sources, and more, and our approach is described in greater detail in the Methodology section.

The decision to review all kinds of material from peer-reviewed articles in academic journals to polemic pieces and short articles in local newsletters yielded a rich mix. Our search took us beyond libraries and electronic databases and into dusty archives to examine the papers of recently defunct Community Health Councils (CHCs) in London as well as the shelves of key voluntary organisations. The nature and quality of the material we looked at was hugely variable. What the material we reviewed had in common was that it all - somehow - included input from older people or their carers.

Academic studies were (sometimes) more persuasive in terms of the purity of their methodologies, but local groups of older people were often extremely interesting on the small details that really concern older people. Also, whereas academia requires its researchers continually to explore new zeitgeists and inspection agencies are largely required to focus on issues relating to current Government policies, older people around London, when asked for their views, often persistently return to long-standing concerns that have not been fully resolved to their satisfaction, or which affect them differently as services develop. Most of the material was more expansive on what older people think about present services than about what they might want for the future, and future wishes are often broad-brush or are framed in opposition to a bad experience of an existing service. It is unsurprising that written material from older people and their organisations does not usually expound a radically new vision for care services, but rather a desire for better access to, information about and quality of, existing kinds of services.

When we began the review, we expected to find rather more "pure" academic material than we actually found. However, our remit was to review material that included the views and experiences of older people and we quickly found that much of the academic material that came to light via key-word searches actually failed to include anything about what older people had said or experienced in relation to care services. Sometimes, articles included an exhortation to include older people in research, but did not do so to any significant extent.

There was also no shortage of articles about how to seek the views of service users including older people, see for example Patmore C, Qureshi H *et al* (2001), but there was a relative scarcity of published material that actually documented older people's views. The other side of the coin is that some of the direct testimonies from older people are presented in a rather unstructured way, where material from listening events and consultations, or from small scale surveys are sometimes short of information to enable a judgment to be made on the reliability of the data. In taking together all of the different kinds of material we hope to give a more rounded and balanced view than would be the case from any single source.

It is evident from all of the literature that older people in London are not a homogenous group. They vary in the ways that all people vary – ethnicity, class, ability/disability, gender, sexuality – and age itself, since an older person may be anywhere within a 30 or 40 year age band! It is immediately clear that the aspect of diversity that attracts the greatest attention is race, culture and ethnicity, while other aspects are relatively neglected. This will be discussed further within the report.

One further difficulty was that it proved difficult and often impossible, to get a specifically London perspective. Our basic screening question was: does the material have information that is *either* directly about the views of older Londoners and their carers about care services and the questions identified in the King's Fund brief *or*, in the case of national material, is there a London angle that can be inferred from the material? Therefore we included material from urban areas that would have some issues akin to London's issues, and we included UK-wide material and multi-centre research material. In the latter it was usually impossible to disaggregate London material, even where the research included work in areas of London. In a few cases we included studies from outside London when they covered important issues or areas of care not included in other, more London-focused, work; for instance the Joseph Rowntree Foundation study on intermediate care services (Petch A, 2003).

Despite these difficulties, we hope and believe that this review will be a useful source of information to older people and their carers and to all of those who are working to plan and deliver better care services for the next generation of older people.

NOTE ON METHODOLOGY

The literature search and review

We collected and reviewed the material between September and November 2004. Each piece of literature was reviewed by one or other of the two researchers. Details about each study or report was noted on a standard pro forma (see appendices). In total we looked at over 160 items. These are referenced at the end of the report.

A full list of the sources searched is appended with key words used where relevant. We found that we had to experiment with a number of combinations of keywords, depending on the particular database and the type of keywords used. It was often difficult to pull out the material we were actually looking for. Most searches for "user views", for instance, initially generated material on how to elicit service users' views. Not all material was accessible through web sites and databases and considerable amount of literature was sought by telephone and email. We conducted a hand search of some key journals, having established the difficulties of identifying the material we sought through key words. Some references were found through citation tracking.

We limited our search to material published in the last five years (since 1998), but this meant that some studies that were included may have been based on data collected a few years previously. Also in that period of time some of the inspection reports and borough surveys may well have been superseded by action to remedy concerns and are only a snapshot of the situation when the inspection was conducted. Some of the London local authorities were keen to stress this point when they provided material. It should also be noted that the time-lag for publication, especially of peer-reviewed material, may result in recent developments not being fully reported by academics, although such material may have been alluded to by other sources, such as local consultations with older people.

We looked at all joint (SSI / Audit Commission) reviews conducted of London social service departments over the past five years (19 in total). Due to the methodology of these reviews, it is usually not possible to disaggregate what older people have said from social service users as a whole (including children and families). In some cases it will be clear that comments relate mainly to older people's services; for instance most concern about discharge from hospital relates to older people, but in other cases, for example use of direct payments, most comments relate to adult services in general and may well not refer to older people's services.

In other inspection reports, for example Audit Commission reviews, Best Value studies and Commission for Social Care Inspection (CSCI) reports it is usually not possible to clearly differentiate the views of older people and their carers from the views of managers of services or others who were spoken to during the course of a review.

It should also be noted that references to some London boroughs appear more frequently in the report. This is mainly because we were able to access material from particular places more easily for various reasons. We actually spent many hours on the telephone to London Boroughs and other agencies trying to find less accessible material, but due to time constraints, we were not able to spend any longer on this activity. However, extreme caution should be exercised in inferring judgments about the relative availability or quality of care services within London from this incomplete picture.

We found more material on some areas of care than others. One third of all the literature reviewed is wholly or partly about home care services. This is due to various factors. Primarily the predominance of this issue in the literature probably reflects the concern of central and local government policy to promote independence for older people and this is largely interpreted as supporting people to stay in their own homes. For older people themselves this is also a primary concern and most, but not all (see discussion below), express their aspiration of independence as meaning staying in their own homes.

A further explanation for the large number of studies on home care services is that this kind of research is probably easier to get funded and to carry out. Due to current policy thrusts, there appears to be considerable willingness to fund research that investigates the most effective ways of supporting people at home and providing domiciliary care services. Also, older people living at home are in many ways easier to research than those in residential care. This is partly because the former group are more likely to be able be involved in research as active participants, due to higher levels of cognitive functioning and lower levels of physical frailty, and also because conducting research in institutions is fraught with ethical difficulties and concerns that people living in institutional care may be reluctant to criticise the services.

Analysis

Together the researchers conducted a thematic analysis, based on the findings noted on the pro forma, and identified around 30 themes. These were then grouped under headings which form the main headings of this report.

ACCESS

There are several aspects of access to care services that are covered in the literature. Some of the material looks at how people are assessed for services and the criteria that are used to make decisions about what services they will be offered, as well as the attitudes that may impinge on assessment and the provision of services. Some of the literature looks at payment for services and how this may facilitate or impede access. It is also relevant to look at how people can find out about what is available and make their views known about care services, as these factors are relevant to accessing suitable services.

Many of the general points made about the problems that older people encounter in accessing services are made particularly by Black and minority ethnic (BME) individuals and their organisations. These points are discussed in this section, where relevant, and further points made by BME older people are also discussed elsewhere in the report.

Care management and assessment

Older people's access to care services is dependent, to a great extent, on the nature and quality of the assessment they receive. In this section, a number of concerns are discussed.

Experiences of assessments – issues raised

A study in Barking and Dagenham found experience of assessment had been variable, but multi-disciplinary assessments generally worked well across agency boundaries. There were differing views about initial assessments, and follow-up assessments/reassessments. In a number of cases, initial assessments had clearly been well planned and executed, with excellent collaboration across different health and social care professionals. There were some difficulties in securing a reassessment as circumstances changed and some people feared that reassessments would adversely affect their level of service provision (Levenson 2001).

Seminars held for Age Concern's debate of the Age (Hunt 1999), reported that during the assessment period for long-term care, individuals often end up with a service the assessor thinks is required, rather than one the individual wants.

In Merseyside, research pointed to the need for co-ordinated assessment and provision and better communication between agencies (McNally 2001).

A review of research in Scotland (MacDonald 2004) found that there was a gap between the support people need and what is on offer. Needs as determined by older people themselves focusing on quality of life and expectations may be different from needs as catered for by health and social care agencies. Gaps in community care could often be traced to agencies not collaborating, not operating as a "network of support" and not referring people on. The report also highlighted the importance of making an individual assessment of carers' needs as a way of strengthening community support.

In looking at assessment and care management, this report (MacDonald 2004) also found that research on assessment practice is scarce; evidence of unmet need and of inadequate practice continues to emerge from the research. The researchers found a variation in the way care management is organised and different interpretations of what it is. Also, they stated that measures of satisfaction have limited use in identifying what aspects of the service people

find satisfactory or what needs to be changed. They found that researchers agree there is a need to agree outcome measures with service users in order to properly assess and monitor care.

A report on older people's priorities for health and social care (HOPe Group 2000) found that assessment was too often limited in scope and fails to take account of the priorities of the individual.

Users' satisfaction with assessment

Interviews with older people in six local authorities, including one in London (Help the Aged 2002), found that greater satisfaction was expressed by older people who had been assessed while waiting for discharge from hospital and by those who needed substantial care packages. Those who experienced the greatest dissatisfaction were older people whose assessments had been relatively simple or for whom the outcome did not match their perception of their needs. People with low level needs or those who have been refused support are at risk of being lost to the social care system.

Another study, conducted in three areas, including one London borough (Moriarty, Webb 2000), found that the content and standard of assessment was very variable. In Havering a CSCI inspection report (CSCI 2004d) also noted that assessments lack detail and consistent structure, and that carers' needs were not considered separately. In Tower Hamlets (Begum, Miah 2004b) service users were generally not happy with the assessment process; they felt that they were not involved or listened to and their needs were not met. There were also concerns about delays in sharing information from assessments with all agencies who need to provide a service.

In Hillingdon (LB Hillingdon 2001) a Best Value Review of assessment and care management expressed concern at waiting lists for assessments and lack of clarity on process.

A study of people with Parkinson's disease, of whom 70% were older people, found that care management had largely failed this group of people (Lloyd 2000).

Carers' experience of assessment

The Nuffield / Department of Health study on social care outcomes (Henwood, Waddington 2002) found that there were continuing problems for carers. There was often a lack of awareness that an assessment had taken place and little evidence of open consideration of carers' willingness to consider caring.

Assessments of carers in London boroughs

Various inspection reports mention carers. The main concerns of CSCI and SSI /Audit Commission inspections are whether carers' needs are assessed separately or not, the quality of carers' assessments, and whether needs are responded to.

Too few separate assessments of carers

- Brent (SSI / Audit Commission 2002a)
- Kingston Upon Thames (2000d)
- Lambeth (SSI / Audit Commission 2000a)
- Havering (CSCI 2004d)
- Hillingdon (LB Hillingdon 2001)

Better identification of carers' needs required

- Hounslow (CSCI 2004e)

Need to better respond to carers' needs

- Enfield (SSI / Audit Commission 1998)
- Waltham Forest (SSI / Audit Commission 2002c)
- Kensington and Chelsea (SSI / Audit Commission 2001c)

Carers involved in service development and the number of assessments has increased

- Hackney.

Care management

One study in north east England (Stanley, Reed et al 1999) provided compelling evidence that the terms "care manager" and "care management" had no meaning to the older people who were interviewed. A hierarchy of questions was developed to identify the care manager or social worker involved. Not one of the older people recognised either the designation of social worker or the role of a social worker involved in their care. The care manager was not recognised as either care manager or social worker. The person who came and assessed the older person's need for residential or nursing care was referred to on a first name basis. They were seen as "friends" but with no idea how the "friends" had found their way to them. No sense of formality was evident in the relationship and no link was made between the "friends" or care manager and social services. There was no evidence that the respondents were aware that their care was being managed. It is suggested that service users are more concerned about finding solutions to their problems than about input from the service deliverers.

Also in the same study, we see that carers were unable to name a care manager or to know that a care manager was involved with their family member, but there was a recognition that the care manager might be connected to social services. There was more recognition of a person being a social worker.

Concerns were raised about care management in another study conducted in seven areas, including one London borough (Ware, Matosevic et al 2003), which found evidence of increasing fragmentation of the assessment and care management process, which could lead to discontinuities of care for users and their carers. This study found that service users were generally satisfied with referral and assessment process, but this may reflect the possibility that those who did not negotiate the referral process would not have been in this study; and also that 32% of referrals do not lead to services being provided, which would have excluded others from making their views known.

Access and eligibility

Many factors combine to affect older people's access to care services, including how they are assessed and how assessments fit into defined criteria of eligibility. Individual and cultural factors also impact on these issues.

Eligibility criteria

An inspection report in Redbridge (CSCI 2004b) found that some confusion about revised eligibility criteria had led to inconsistent practice and potential inequalities in provision. A

Best Value report in Hillingdon found that there was a perception that eligibility criteria in home care were perceived to exclude housework and cleaning which impacts on quality of life for older people. In Haringey, a joint review (SSI / Audit Commission 1999) concluded that there needs to be greater clarity in eligibility criteria for services.

A Help the Aged study of six local authority areas, including one in London (Help the Aged 2002) suggested that most of the problems older people experience in accessing social care are related to budgetary constraints; for example, information on services available and how to access them is variable and eligibility criteria have been tightened and services restricted or cut. This report asserted that a reduction in staffing levels had increased waiting times for assessment and services. The report also noted that the provision and quality of care for older people is poorer than for other user groups and older people's expectations are low. Also, confirming the findings of other studies, this report stated that some groups (for example, people from BME communities and people with mental impairments) experience greater problems in accessing services.

It is also a matter of concern that people who had been denied a service on grounds of eligibility or waiting lists were not offered advice about alternative sources of help (MacDonald 1999).

Organisational issues and processes

Sometimes, organisational issues and systems restricted access. A small focus group in Hillingdon found that older people had difficulties in accessing social workers. Older people complained that social services do not return phone calls and they never get the same person on the phone and so have to repeat all the background to their request (Hillingdon CHC 1998). Problems accessing help on the telephone were also identified in Waltham Forest (Age Concern Waltham Forest 2004c). Some older people felt that the call centre was "blocking" enquiries, and older people were in distress. Telephone manner was important too, and BME elders in Waltham Forest wanted to see a change of culture in statutory sector staff and the voluntary sector, with these agencies becoming more enabling. For example, they said that professionals need to offer information and not wait for questions. Also in Waltham Forest, there were reported problems in accessing services because of delays in answering calls and music on the line was disliked by some (Age Concern Waltham Forest 2004a). In a Hillingdon report, older people commented that there was a need for a single point of telephone access to services and also for a quick responsive service to emergencies (LB Hillingdon 2001).

Complicated forms and procedures were also raised as a barrier to accessing services. These were experienced as unduly complex, unfriendly and inflexible by those trying to access services for themselves, and by those negotiating the system on behalf of older relatives and friends (Hayden, Boaz et al 1999).

In Barking and Dagenham, the report of a listening event (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004) also stated that many forms are confusing for older people and they do not understand the reasons for these forms or fully understand the assessment process.

Access issues for BME communities

An Islington study (Livingston, Leavey 2002) showed a complex picture relating to access and BME communities. For example:

- African and Caribbean people used day care and other social services most frequently
- Living alone is the strongest predictor of using day services
- Cypriots and African and Caribbean respondents received less informal care then UK-born counterparts
- Immigrants in general accessed primary and community health and social care services at least at the same level as UK-born older people
- African and Caribbean people have poorer physical health and this may account for their greater contact with health and social services.

Often, there are a cluster of factors that go together to restrict access. For example, in one study involving Chinese older people (Wai Kam Yu 2000) nearly all the respondents (97 per cent) said they found it difficult to use social services. Difficulties included inability to speak English and particularly to understand social services jargon; lack of information about services and older people's rights to these; and the costs of using services. In that study, the focus groups (which also involved professionals) suggested that services need to look at increasing Chinese older people's participation in society, raising the visibility of their needs, improving access to services, raising their expectations of retirement and providing life-long learning opportunities. South Asian people also reported a lack of access to appropriate services (Bowes, Wilkinson 2003) and in another study (Bowes, Dar 2000) it was suggested that South Asian older people had very little knowledge about social services and welfare benefits. The home help service was used by 7% respondents and only one received a package of services. Referral to mainstream services by GPs or community-based groups was rare and the unmet needs of people living in family households tend to be hidden. Help with household tasks was a key concern, but this community had little knowledge of how to get it.

Several studies refer to a low take up of social services by BME older people. One report (Age Concern 2000), found this was not attributed to a low level of need, but to a lack of culturally sensitive and appropriate services, and lack of information in accessible formats (for example, advice and information in English, lack of interpreters, unsuitable food). Similarly, a study in Enfield (Yahioglu 2004) identified a number of access issues for the Greek and Turkish communities in respect of mental health support for older people, including:

- Isolation/living alone
- Lack of family support and breakdown of extended family units
- Transport
- Multiple health problems
- Low expectation/life expectancy (sic)
- Depression not seen as a mental health problem
- Language
- Uptake of culturally appropriate services through word of mouth rather than translated material
- Gender issues
- Lack of understanding of the term "mental health" by first generation Cypriots
- Stigma regarding mental health within both Greek and Turkish speaking communities.

BME people in Barnet, Enfield and Haringey (Age Concern England, undated) also felt that access to services is limited by a number of factors specific to BME elders. Service providers were urged to listen to and understand BME older people, respecting cultural and religious

beliefs and treating people with dignity. The report stated that BME elders need access to a range of activities and services which meet their needs. Voluntary and community groups played an important role in providing access to services.

A recent report from Waltham Forest (Age Concern Waltham Forest 2004b) showed that BME older people want better access to services for disabled elders. Specifically, they wanted social services to visit older people more and act on needs as requested. They noted that some elders try to be independent and find it difficult to ask for services.

Other issues that may impede access

Studies in Merseyside (McNally 2001) identified additional reasons why some people do not access or accept services. For example, there are worries about loss of benefits or privacy, and also some concerns about staff behaviour.

Another Waltham Forest report, of consultation with older ethnic minority people and refugees (Age Concern Waltham Forest 2004a), raised issues about access to services that were not specific to BME communities, including:

- Issues about the "disabled grant" (delays and inefficiency)
- No continuity of staff
- Impression of prying, duplication of information, length of forms
- Communication between agencies/departments get lost.

Other access issues were reported in studies outside London. For example in Wales (PRIAE 2000) it was reported that home care and other areas of social service are not entirely familiar to many elders and people were unaware of day care, home helps, 75+ health check and a range of financial benefits.

Interviews with service users soon after their return home from hospital (Roberts 2001) found that in relation to getting access to healthcare all participants named their GP (or others at the practice) as contact points and also mentioned people at the hospital. However, contact points to access social care were consistently less well identified; there was a general lack of knowledge and lack of precision about which agencies they would go to.

Information, Advice and Advocacy

Older people across the country have been concerned about information, advice and advocacy. It is difficult to separate these categories and indeed, one study (Raynes, Margiotta et al 2003) stated that information and advice are invariably linked together. Despite London's complexity and the relative mobility of some of its population, there are no reports of specifically London aspects to these concerns, except in so far as there are clearly particular information issues for BME communities, who tend to live in London and other major urban centres.

Perceived lack of information

In Barnet, a study showed that there is a vast array of information and advice provided by both statutory and voluntary organisations (Kerr, Kerr 2003), but often it is on all aspects of community life and not specifically for older people. Older people do not always know that such information exists; nor do they always know how to ask the questions that will elicit the answers they are looking for.

One study (Henwood, Waddington 1998b) points to a lack of adequate information on eligibility for services, financial help available, and a lack of independent advice on, for example, moving into supported housing and home adaptations.

In the past most information material has reflected the concerns of professionals with little input from older people's perspectives and this was reflected in content and format. Users were often disappointed with the provision of information supposedly aimed at their needs (Raynes, Margiotta et al 2003).

In Camden, a Best Value study (Dalley, Hadley 2000) showed that 25% of older people in residential care said that they had been given no information to help them make the decision about their choice of home. Another study found there was also a lack of advice for frail elderly home-owners across five areas of England (Wright 2002). Interviews with privately paying residents and relatives showed that it was common for both groups not to have understood the complexities of the current means test before admission. A minority of relatives had talked to a local authority social worker. Some had gone to a care home provider for advice, some to banks, financial advisers and friends. In Slough, a Best Value Inspection (Housing Best Value Inspection Service 2001) showed there was no up to date information available on the services available to older people in supported housing. In Newham, brochures on housing choices were not seen as sufficient to enable older, frail people to make choices (Newham HIMP 2003).

A Redbridge inspection report (CSCI 2004b) stated that service users are not routinely and consistently provided with information leaflets prior to or during assessment process; service users and carers did not have a good understanding of their rights or what resources were available to them.

Generally older people do not feel they are given enough information about the services available or those provided to them by social services (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004, LB Hounslow 2003, Levenson 1999). Data gathered in seven local authorities, including one London borough (Ware, Matosevic et al 2003), showed that users and carers had insufficient information to make an informed choice of care services. In some cases users found it difficult to know what to ask for unless there was some indication of what services were available. A Havering inspection (CSCI 2004d) suggested that information was quite good and most people received information about services during the care planning process, but it was not generally available to people before they were in the system. In Hounslow, A Best Value report (LB Hounslow 2003) suggested that those who were aware of the information available considered it good quality, but many were not aware of it. A users' panel had made an improvement to the quality of information.

One research study (Hayden, Boaz et al 1999) reports that older people's views of information depended on their experiences of accessing information during their lives. There tended to be a spectrum from those who confidently and actively sought out information, to those who were passive recipients and tended to rely on personal networks as their main source of advice.

A study in six local authorities, including one in London (Help the Aged 2002), concluded that the overall sense from users was that information is "managed" to control demand.

Information about health and healthcare services relevant to care services
A few studies indicate specific deficits in information at and around the time of discharge from hospital (Bexley CHC 1999, Guest 1999, Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004). There are mixed responses to the amount of information given to patients on their medical condition (Bexley CHC 1999) and one mention of patients (of unspecified ages, but assumed to include mostly older people) not having enough information about the district nursing service (Barnet CHC 2003).

Barriers
One of the most important recent studies (Quinn, Snowling et al 2003) showed that older people experienced barriers in accessing information, advice and advocacy in three stages:

1. Becoming aware that there was information, advice or advocacy that could help in their situation;
2. Gaining access to appropriate and comprehensive information and advice; and
3. Receiving practical assistance to act on the information and achieve a solution.

This study found that:

- Older people welcomed advice that helped relate information to their particular circumstances, and assistance to obtain the services they needed. The volume of information available could be as problematic as an absence of information. They did not generally find distinctions between information, advice and advocacy meaningful.

- Older people valued information that was topic-based, rather than the agency-based information that was more frequently offered.

- Older people had diverse approaches to obtaining information. Different modes and styles of information suited people at different times and in relation to different topics. They wanted timely information, often at a point of change or crisis in their lives, and comprehensive information actively offered in their first language at such stages

- Older people desired continuity of contact, to avoid having to retell their story to new people. A follow-up service was also appreciated, ensuring a solution was achieved, rather than simply being referred on to yet another potential source of information.

- Services struggled to provide accurate and comprehensive information to older people, in the absence of resources to develop and maintain information databases.

Other studies show similar and complementary findings. For instance, an Age Concern submission to the Royal Commission on Long Term Care reported problems with getting information about services. Different agencies for example, GPs, social services, do not hold information about services available from other agencies and give unreliable information about whom to contact (Age Concern 1998).

Sources of information

The literature contains a number of references to sources of information, both in terms of what people have found and what they might like. Focus groups in three settings (sheltered housing complex, a rehabilitation and assessment ward for day patients and a local healthy hips and heart group meeting in a hospital) showed that:

- None of the people in the focus groups used the Internet
- Citizens Advice Bureaux, resident warden in sheltered housing and peers were the most common sources of information mentioned
- Face to face contact was most effective and appreciated (Raynes, Margiotta et al 2003).

In fact, views on the place of new technology were mixed. There was widespread concern about the growth of new technology in information delivery, such as touch-tone phones (Hayden, Boaz et al 1999), but also there were positive statements about computers and older people's desire to have access to them (Walker, Radford 2000, Newham HIMP 2003). However, a survey of local authority websites in an unspecified area of England showed that only 3.5% had a direct link to issues for older people (Raynes, Margiotta et al 2003).

Information in leaflets remained important and a Hounslow inspection report commented that there was a good range of leaflets and information packs, but there was a need to review how they were displayed (CSCI 2004e).

One study found that some older people had become quite adept at working out how to get information and advice. Others were still very unsure how to get it and even people who felt quite well informed sometimes reported uncertainty about what they would do out of hours, or felt that they had had difficulty in finding out information about specific services (Levenson 2001). The individuals and agencies who were mentioned in this study as initial sources of help, information and advice included:

- Family
- "First contact" people at local authority
- "The council"
- Duty social worker
- GP
- Nurse
- Nurse - liaison officer
- Duty Community Psychiatric Nurse
- Consultant's secretary
- Carers' group
- Disablement Association
- Crossroads
- Emergency personal alarm system.

An Audit Commission report on older people and independence (Audit Commission 2004) states that being able to obtain information from an independent source is important.

Getting information - what older people want

The major study on information needs (Quinn, Snowling et al 2003) found that older people's preferred solutions included: an information bank to provide a comprehensive and updated source of information, and an information centre to provide a point of contact for older

people. In Waltham Forest, older people asked whether GP premises could be used to provide information as all older people had GPs (Age Concern Waltham Forest 2004c). The same report also showed that older people were willing to take responsibility for themselves, for example, by hunting out information. They also pointed out that the voluntary sector needs to use national policy to the advantage of older people, for example, the NSF standard on rooting out age discrimination. GPs were also seen as potential information sources in other studies (for example, Age Concern England, undated).

Sometimes older people wanted particular kinds of information. In Merseyside (McNally 2001) older people specifically wanted accessible information and advice on benefits, information about services and how to access them and written information that could be understood. In Hillingdon, the CHC found that patients should be provided with information about Crossroads (Hillingdon CHC 1998). Focus groups in an unspecified area showed that older people wanted advice on community issues for example, making pavements safer, refuse collection, local amenities, mobility and transport, aids for help in the house, financial concerns and services provided by statutory and voluntary organisations. They also wanted lists of agencies and telephone numbers (Raynes, Margiotta et al 2003). This study defined the characteristics of good practice as:

- Information and advice being focused on older people's needs rather than on the structure of the services that exist
- Older people's views being taken into account when producing the material
- Involvement of older people in the design and production of material
- Provision of information and advice in variety of formats, taking into consideration language and literacy difficulties
- Investigation into ways of distributing information and providing access to it for older people who are frail, housebound, vulnerable or have mobility or sensory impairments.

The need for accessible information for older people, available in different formats and at places they frequent was also stated in the report of a Newham workshop (Daines 2002). Another Newham event reports older people as wanting an information strategy which works, with outreach work, and other ideas such as friendship links (Newham HIMP 2003).

A major study of the attitudes and aspirations of older people (Hayden, Boaz et al 1999) found that older people wanted the removal of barriers to independence. The provision of more accessible, user-friendly information was seen as one way of doing this. Most respondents in this study felt that there was a need for better information on a whole range of issues, although they were unsure in what ways information could be best improved. Better information was thought to be about quality as much as quantity. Older people felt that information and advice needed to be personalised and customer focused. Some people mentioned the advantages of having a named person attached to their particular case and the benefits of a 'one-stop shop' for all information. A number of focus groups within this study suggested developing an enhanced information role for the 'professionals' that older people already have contact with, for example, GPs, community centre and day centre workers, Asian language speakers.

One report pointed out that as more and more people become involved in providing care services, a single point of information and contact would save all concerned a great deal of frustration (Hunt 1999).

Information for BME communities

Other issues for BME communities are dealt with more fully elsewhere in this report, but as so many of these issues pertain to information that they also merit a mention here. The main themes that arise for BME older people are:

- A lack of information and knowledge about services and older people's rights to these (Wai Kam Yu 2000, MORI 2002, Bowes, Dar 2000, Bowes, Wilkinson 2003).
- People from BME backgrounds are more likely to say there is sufficient information available than those from white backgrounds (MORI 2002).
- Information should be disseminated more widely (Age Concern England, undated).
- Information is not always available in appropriate languages and formats, with interpreters, where necessary, but it should be (Age Concern England (undated), Age Concern Barking and Dagenham 2000, Patel 2001, Help the Aged 2002, Ware, Matosevic et al 2003, Age Concern 2000, 2004c, Age Concern Waltham Forest 2004b).

In addition to making points about languages and formats, BME older people in Waltham Forest pointed out that better information is required about older people's services before reaching the age of 60 (Age Concern Waltham Forest 2004b).

Where there are reports of information in relation to specific BME communities such as the Chinese community (Help the Aged 2001b) they tend to raise issues that are common to other communities too, except for specific language needs, for example:

- Access to information translated into Chinese is often limited and its quality and presentation variable
- Information is rarely available on audio or videotape
- Chinese people receive insufficient info on hospital, housing, welfare and transport.
- They do not always know what rights or choices they have
- More information is needed on home care and charging.

Finally, it was suggested that information on BME communities was not always used systematically to build population profiles for planning purposes (SSI 1998).

Information for carers

Better information (including good written information) is required for carers about local services (Audit Commission 2002a). These needs were not always met (Moriarty, Webb 2000).

A Bromley study (SSI / Audit Commission 2001d) suggested that charitable organisations providing services supporting older people with a mental illness were also a good source of advice and information to carers.

Advocacy

Several studies raise the use of advocates as a means of improving information about care services for older people, and helping them to exercise informed choices. One study (HOPe Group 2000) asserts that independent local advocacy services are vital to support older

people when key decisions and choices have to be made. A study conducted in Barnet (Kerr, Kerr 2003) found that:

- Older people are and can be effective advocates for their peers
- Groups, both organised and informal or social, can often provide the information and advice sought by an individual
- Advocacy organisations need to be funded appropriately.

Complaints and redress

The literature on older people and complaints mostly highlights the problems or reservations that older people have in making complaints and seeking redress if they have a problem with care services. There is also a small amount of material about the level of satisfaction with the complaints systems.

Do older people know how to complain?

There is a great deal of material in the literature about older people's concerns about quality, access and information in relation to care services. However, there is a relatively small amount of information about older people's use of the complaints systems. This may reflect a lack of use, and lack of knowledge of how to make a complaint. Inspectors in Hillingdon reported that just over half of older people sampled in that area knew how to make a complaint, but those met by inspectors had not received information on the complaints process (2004c). Elsewhere (but in an undisclosed area), many more knew how to make a complaint about healthcare compared to social care (Roberts 2001). A report of a Newham workshop says there is a need for a common complaints system for older people to cover all services (Newham HIMP 2003).

Fear of complaining

In Barking and Dagenham, older people did not feel able to complain as they feared losing the little support they have available to them (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004), and consultation in Tower Hamlets found the same (Begum, Miah 2004b). In Harrow, domiciliary care service users were unwilling to complain about unsatisfactory service or inappropriate billing for fear of reprisals (LB Harrow 2004).

Are older people satisfied with the complaints systems?

In Harrow, a high number of home care service users were dissatisfied with the way their complaints had been dealt with (LB Harrow 2004). In Lambeth, less than half of users of domiciliary care services (46%) said that they had been contacted by Social Services to check whether or not they were satisfied with their service, and only 41% said that they had been advised on how to comment or make a complaint about their service (Lambeth 2003)

Improvements

However, in Newham, a clear improvement was reported in the number of residential and nursing homes with publicised complaints procedures. By December 2000, 98% of homes had a complaints procedure and over 9 out of 10 publicised these procedures (Darcy 2001). Nearby in Redbridge, the complaints process had improved but most users and carers did not know how to complain and had not been provided with complaints leaflets (CSCI 2004b).

BME older people and complaints

One report suggests that BME elders may lack confidence for example to complain (Levenson 1999) while another report from Tower Hamlets suggests that the Vietnamese community may be the most reticent about expressing views about their services (Begum, Miah 2004b).

Ageism and age discrimination

In other sections of the report the existence of ageism and age discrimination can be inferred (see sections on access and eligibility, and quality, for example). However, a few of the reports examined in this review refer directly to ageism and age discrimination, and they are summarised here as they are relevant to accessing services.

The effects of ageism and age discrimination

In Barking and Dagenham a cross borough listening event heard about feelings of disempowerment amongst older people. They reported that many staff come across as patronising and older people feel they are treated with a lack of dignity (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004). A statement of older people's priorities in health and social care (HOPe Group 2000) called for equal access for older people to health and care services and said that ageism is no more acceptable than any other form of discrimination. Another meeting of older people felt that the distribution of resources was unfair and ageist (Levenson 1999).

Specifically, older people experienced age discrimination when crossing the social services administrative boundary between 'adult' and 'older persons' services (Clark, Gough et al 2004) and a report from a large meeting of older people under the aegis of the Greater London Authority claimed that ageism in hospital is a huge issue (Mayor of London 2003). Having consulted with older people, the Audit Commission agreed that changes were needed in attitudes to ageing (Audit Commission 2004).

PAYING FOR CARE

There is a considerable amount of material in the literature about the concerns of older people on the issue of paying for care services, and the impact this may have on access to suitable services. Such material can be found in the academic literature as well as the material that comes from reports of meetings and events of older people. There are no discernible differences in the conclusions of material from London or elsewhere.

Who pays for what?

A small scale interview project set up to investigate the implementation of fairer charging policy introduced in November 2001 found that none of the 11 older people interviewed disagreed with the principle of paying towards the cost of care, but they thought it was unreasonable to pay such a large increase (Thompson, Matthew 2004).

A large UK-wide conference of mostly Chinese older people and their organisations (Chau, Yu et al 2002) reported that participants felt that:

- The government should set up special funds to enable Chinese organisations to provide services for Chinese people
- The government should provide resources to enable Chinese workers to attain qualifications to serve Chinese people
- Allowances should be provided for carers over 60 years old.

An Alzheimer's Society study, (Alzheimer's Society 2002) which used feedback from carers of people with dementia to explore whether the Government's policy of "free nursing care" (announced in October 2001) is "unfair and unworkable" as the Society had labelled it, reported that the most help a person can expect to receive, under the free nursing care policy, would (at that time) be £5,720 per year in England. Some people have been caring for partners with dementia for more than 20 years. They made the point that in the past some of the care was provided in a hospital environment through NHS care, but this was not usually the case now. The report added that the Government had intended that the reimbursement of "free nursing care" would lead to a reduction in residents' fees, but this had not always happened and there were a lot of problems. For example:

- Because the reimbursement was given to the care home rather than the residents carers feel angry and cheated. Examples are cited of care homes raising fees to match the element of reimbursement so not passed on to relatives / residents
- People with dementia put onto lowest band of reimbursement (£35 per week)
- People with dementia assessed as not needing nursing care at all
- People with dementia who are at home or in residential homes get no financial help at all as their care is provided by very skilled staff, but they are not always nurses - the administration of free nursing care policy is usually based on setting rather than needs.

All of those points were seen as having an impact on access to suitable care, and a sense of injustice about how it was paid for. This point was also confirmed by reports from Age Concern England's Debate of the Age, which showed that older people were worried by the changing policies on financing all aspects of care (Hunt 1999). The Debate of the Age called for the Government to regularise charges for domiciliary care. Another survey of 60-75 year

old home owners across the country reported that 92% expressed concerns about state's commitment to care or the quality of care (NOP Corporate and Financial 1997).

One study (Henwood, Waddington 1998b) also noted a sense of injustice and lack of fairness as older people felt they were having to pay twice for their care (through tax and National Insurance and then again as users of services). This was particularly clear in the oldest groups of participants. There was also a sense of injustice at the penalty on thrift – people who had savings had to contribute most. Having to sell the family home was a particularly emotive subject. Most people accepted they should pay something towards their care, but did not think it was right they should end up with virtually nothing for years of work and saving. Private insurance was regarded as too costly and unreliable but support was expressed for some kind of compulsory state insurance to cover long term care needs. This study reflected the views of 64 participants in 7 focus groups, who were identified with the help of statutory and voluntary agencies and UNISON, under the aegis of Help the Aged; it included groups in day centres, a day hospital, residential homes and a nursing home. Similar views were also reported from other studies, (for example Thompson, Matthew 2004).

A report on a recent consultation programme in Tower Hamlets with 145 older people from BME communities on home care and intermediate care services also found that service users felt that it was wrong that some people have to pay for services because they have assets and yet they were free for others (Begum, Miah 2004b).

Variations in charging policies

There are indications of concerns from older people about the variations in charging policies and the impact this may have on accessing care (Wright 2000 and Wright 2002). The literature shows that:

- There were variations in local authority community care packages.
- There were local variations in assessing financial situations.
- Older people who owned their own homes were failing to obtain needs assessments. A rationing strategy in some areas was to decline to do a needs assessment for residential care when the person had more than a certain amount of money. Though not officially the policy of managers, policy was not always respected by their staff.
- There were some problems in entering a care home without a local authority contract, for example rates might be higher; there was no guarantee of the authority making a contract with that provider once the resident's own assets had diminished.
- There were local variations in the treatment of a carer remaining in a property.
- There was variation in the treatment of a spouse in the community.

Concern was also expressed about the relative poverty of very old people (Henwood, Waddington 1998b) and inequities in benefits and concessions provided to older people in different authorities (Henwood, Waddington 1998b and Help the Aged 2002). Other reports

confirm that charges for home care and day care vary between authorities, resulting in serious inequities. Charging may result in people refusing help.

A workshop in Waltham Forest (Age Concern Waltham Forest 2004c) of Asian older people found that there was an issue about the cost of lunches and refreshments at social clubs. The report of the Help the Aged HOPe group (HOPe Group 2000) made the point that charging for day care has adverse effects for BME people for whom the community centre may be the sole contact. This report also suggests that there is considerable inequity in charging policies across the country.

Concerns about charges

Some of the literature that reflects direct consultations with older people shows concerns about pensioner poverty, as a context for concern about paying for care. For example, a consultation in London in 2003 indicated that Attendance Allowance was used for daily living, food and bills, rather than care (Mayor of London 2003).

Other studies showed that older people are worried about the lack of security in their life, for example lack of money, problems arising from maintenance work and living environments (Chau, Yu et al 2002).

The literature also indicates concerns of older people about the level of charges they have to pay. In the Bangladeshi and Vietnamese community older people fear accessing the home care service in case their benefits or other services are affected (Begum, Miah 2004b). That study also found that personal financial details required in assessments were felt to be intrusive.

A series of seminars were held in London, Edinburgh and Leeds in 1998 to establish the content and direction for long term care from the perspective of elders and their carers from BME organisations. The report of the London seminar (Patel 2001) indicated much concern about paying for care. Women were concerned that they have not worked and so have not built up savings, and high unemployment amongst BME groups resulted in a lack of savings. People felt that had not got not enough money to live on and therefore did not know how they could pay for care. Participants at this seminar considered means tests justified if people had a large amount of funds. They agreed on the statement:

> "Those who have the means must pay, those who have no means must receive care. This must be occur without neither hesitation nor humiliation".

They also wanted to be economically independent though pensions are very low amongst BME communities.

Concerns about charges for day care service were reported in a Wandsworth survey of older people (Wandsworth Borough Council 2000) and concerns about increases in charges were reported in a very recent survey about domiciliary care conducted by Age Concern Harrow (LB Harrow 2004) and by two out of the eleven people interviewed in a small scale study to investigate the implementation of fairer charging policy introduced in November 2001 (Thompson, Matthew 2004). That same study also found that:

- One person was paying double the hourly rate for care as she needed two carers to get her in and out of bed
- Quality had not improved with increased price.

A report by Croydon CHC (Croydon CHC 2002a) stated that the social services department charged for some of their services at weekends and overnight and that could be confusing.

Some residents in sheltered housing worried about paying for their future care (Kellaher, Schroeder 1998).

One study in Camden reported difficulty of paying in the way that suits the service user, for example, cash or weekly payments, not quarterly payments (Dalley, Hadley 2000).

Satisfaction with charges

Some reports indicate a reasonable level of satisfaction with charges. In Newham, 88% of people thought the meals that were delivered to them gave value for money (Regan 2001a). In Havering, most older people thought that they were charged a fair amount for the services they received though less than half knew how the charge had been calculated (CSCI 2004d).

Understanding of charging and value for money

It is not always easy to assess whether satisfaction or dissatisfaction with the level of charging is underpinned by knowledge about how charges are calculated. For example, the Hanover Housing Group provided all residents with a full breakdown of rent and service charges, but between a quarter and a third of residents felt unable to assess whether the charges represented value for money. Of those expressing an opinion, over 4/5 were satisfied that value for money was provided (Bartholomeu 1999).

In Hillingdon, an inspection report showed that most older people thought they were being charged a fair amount for services, but less than half knew how charges had been calculated (2004c). In Camden, a study found a lot of confusion amongst older people in sheltered housing about how they were charged and what the charges were for various services associated with the alarm and warden services and rent (Dalley, Hadley 2000).

Self-funders

A number of issues are reported for people who pay for their own care (in a variety of care settings). BME older people in Waltham Forest made the point that older people who can pay still need advice/assistance (Age Concern Waltham Forest 2004a). There are also specific problems for those in private and voluntary sector homes who are funding their own care. They may be charged privately by homes for specialist equipment such as pressure sore mattresses, when they are available without charge to individuals through the NHS. This was compounded by a lack of routine reassessment of such people to see if they have become eligible for NHS funded care (Age Concern 1998).

UK wide research on people admitted to care homes on a self-funding basis (MacDonald 2004) revealed that they had received relatively less in the way of support services prior to admission than publicly funded people. Self-funding people were less likely to be physically dependent, but more likely to suffer from diseases or depression and to have experienced social isolation in their own homes. This suggests an unmet need for community based

services offering social contact and interest as opposed to intensive personal care. One study showed that the use of private home care services is greater amongst women than men (Stoddart, Whitley et al 2002).

A study of older people following discharge from hospital found that they perceived themselves to have more control over their care if they paid privately (Roberts 2001).

Further studies (Wright 2000 and Wright 2002) confirmed that there was a lack of advice for frail older home owners. Interviews with privately paying residents and relatives showed that it was common for both groups not to have understood the complexities of the current means test before admission. A minority of relatives had talked to a local authority social worker. Some had gone to a care home provider for advice, some to banks, financial advisers and friends.

Self-funding by people with dementia may involve fees of more than £500 per week. People who self fund often subsidise other residents and pay more than those supported by local authorities. Furthermore, people with dementia can often remain physically healthy for many years and may require care for a long time (Alzheimer's Society 2002).

Direct payments

Direct payments are a way of facilitating access, choice and independence for older people. Although the use of direct payments has increased steadily, older people remain less likely to choose this option of arranging their care.

Fora in Glasgow and Birmingham were held to consider housing and inclusion of older people in 2025 (Fisk 1999). They concluded that direct payments schemes might be explored in the context of paying greater attention to the practical needs of older people.

Older people's experiences of using direct payments

A recent report from CSCI (CSCI 2004a) found that most people who use direct payments find them excellent, and it has enabled them to make the most of their lives by allowing flexibility, choice and control over their care packages though it should be noted that the ages of those attending the events on which their report is based are not given, so it is not possible to be certain of the extent to which their findings apply to older people.

One of the more detailed studies on this issue (Clark, Gough et al 2004) shows that:

- Older people receiving direct payments reported feeling happier, more motivated and having an improved quality of life than before. There was a positive impact upon their social, emotional and physical health.
- Direct payments enabled Somali older people to employ personal assistants (PAs) who shared their language. Accountancy services dealing with banking and administrative requirements were essential in overcoming language and literacy barriers.
- Support services were crucial in enabling older people to use direct payments. The major difficulty lay in meeting audit and administrative demands, necessitating ongoing assistance from support services. Local authority funding does not always account for this.

- Most older people employed PAs. There was a call by older people for direct payments support services to maintain registers of assistants to ease the recruitment process.
- Some older people used PAs for social activities and/or alternatives to institutional respite care. They were rarely allocated hours for this in their direct payments packages, so they had to be 'creative' with their hours and fund additional costs themselves.
- Older people could probably derive more benefit from direct payments were it not sometimes assumed that older people have a restricted lifestyle.
- Older people experienced age discrimination when crossing the social services administrative boundary between 'adult' and 'older persons' services.
- Care managers are key to giving older people access to direct payments, but direct payments are yet to become part of the culture of care management. To make direct payments a mainstream option, care managers said they required sufficient knowledge, support from line managers, time to think and work creatively, and a clear understanding of the role of direct payments support services.
- The researchers recommend that funding of support services should reflect their value both to older people and to the local authority.

In Portsmouth, some research took place in the pilot phase of a scheme to give older people more choice and control over their support arrangements. It aimed to learn about issues that older people might face when considering whether to take up direct payments and the issues that local authorities might face when implementing direct payments with older people and more generally when seeking to give older people more choice and control over services (Clark, Spafford 2001). It found:

- The minority of older people who chose the personal assistant option received a high quality service. The main barrier in taking up this option was a lack of social networks to find someone suitable
- The lack of a support scheme and a designated direct payments worker probably increased the pressures on care managers and resulted in lower take-up and less creative use of the scheme
- The role of informal carers in providing 'third party support' was not clearly defined. In some cases, carers seemed to use the scheme to increase their own choice and control
- The pilot highlighted tensions for care managers between promoting user empowerment and protecting users from 'risk' and exploitation; and between meeting individual needs better versus ensuring equity in the use of rationed resources.

The CSCI report (CSCI 2004a) noted that the main barriers stopping people from getting the choice and money through direct payments include:

- Some people find it difficult to understand how direct payments affect other benefits that they receive
- People also said that dealing with employment and administrative issues on their own, or having an unreliable support service, can be a major source of stress to them
- Recruiting and employing staff could be difficult - in some areas the workforce does not have people with the required skills
- People find it difficult to access and pay for training for their care staff
- Some people are worried about employing staff without being able to do a Criminal Records Bureau check. Lack of clear information

- Patronising or restrictive attitudes towards people who might want to use direct payments, and an unwillingness to devolve power from professionals to individuals.

Take up of direct payments in London

The take up of direct payments is an issue in a number of inspection reports of London boroughs.

The recent CSCI report of Havering's older people's services (CSCI 2004d) found there was low take up of direct payments for older people. The report of the joint review in Hackney (SSI / Audit Commission 2003c) stated that people need to be helped to use Direct Payments, though this was not specifically about older people.

The CSCI report of the inspection of older people's services in Hounslow (CSCI 2004e) found that good progress had been made in increasing direct payments. In addition a number of joint reviews reported that direct payments were increasing, though, as noted above, this may not specifically relate to older people:

- Good start to the use of Direct Payments and should now be extended to more users – Redbridge (SSI / Audit Commission 2000c)
- Excellent Direct Payment packages – Waltham Forest (SSI / Audit Commission 2002c)
- Good use of Direct Payments - Greenwich (SSI / Audit Commission 2002b).

QUALITY

Defining quality

There are a few studies which focus on establishing definitions of quality in care services from a user perspective or which attempt to discern user-defined outcomes for measuring the quality of care. Discussions with older people, as service users, about quality of care are often intrinsically linked with discussions about quality of life. In other studies indicators of quality might be inferred from those issues which older people highlight as important to them.

Quality of life

The fundamental issues felt to affect quality of life are housing, health status, social integration and independence (Boaz, Hayden et al 1999, Beaumont, Kenealy 2003, Henwood, Waddington 1998b, Raynes, Temple et al 2001b). Quality, independence and autonomy are generally viewed by older people as being associated with staying in their own homes, though there are some exceptions to this.

Food and management of continence are also everyday issues which considerably affect older people's quality of life. The former appears frequently in the literature about older people's concerns and both are discussed briefly below.

Quality of care services

One study concluded that older people know what constitutes a quality service (Help the Aged 2001a). The following issues are identified consistently as indicators of a quality service for older people:

- The extent to which independence is facilitated (LB Croydon 1999, Boaz, Hayden et al 1999, Raynes, Temple et al 2001b)
- The facilitation of social networks and activities, company and conversation (LB Croydon 1999, Raynes, Temple et al 2001b, Barnet CHC 2001a, Help the Aged 2002, Netten, Ryan et al 2002)
- Choice (LB Croydon 1999)
- Flexibility and timing of services and older people's control over their care and daily lives (Netten, Ryan et al 2002, LB Croydon 1999, Raynes, Temple et al 2001b, Patmore 2001, Francis, Netten 2004, Tester, Hubbard et al 2003)
- The ability to respond to individual needs, including low levels of need (Netten, Ryan et al 2002, Raynes, Temple et al 2001b, Boaz, Hayden et al 1999, Henwood, Waddington 1998b, Clark, Dyer et al 1998)
- The extent to which older people are involved and listened to by care staff and providers (Barnet CHC 2001a, Raynes, Temple et al 2001b)
- Continuity of care (LB Croydon 1999, Raynes, Temple et al 2001b, Tester, Hubbard et al 2003); particularly in terms of consistency in care staff, but also other aspects, for example meals being delivered at regular times
- Access to transport (Boaz, Hayden et al 1999, Help the Aged 2002, Raynes, Temple et al 2001b)
- Communication between service users, providers and care staff (Raynes, Temple et al 2001b, Boaz, Hayden et al 1999, Tester, Hubbard et al 2003)
- Access to specific services for BME people (LB Croydon 1999)
- Adequately trained staff (Raynes, Temple et al 2001b).

In addition attention to personal preferences and small details are often found to be very important. In one study (Patmore 2001), for example, an older person's most important quality issue was to have her tea made weak enough. All of these issues are discussed in more detail elsewhere in the report.

Choice

There are various dimensions of choice referred to in the literature. Choice can be seen as plurality of provider, the ability of older people to make choices within a service, and the ability of older people to make major decisions about their lives and end of life.

Plurality of provider

Having a plurality of providers is clearly seen by inspection agencies as driving choice (SSI / Audit Commission 2002d, CSCI 2004e). There is also some evidence that older people too view having a range of services on offer as important in order to promote choice (Hunt 1999). BME communities often feel they are not served well by mainstream services and so would look for a plurality of providers which offers the possibility of having specific services for particular communities (Patel 2001, CSCI 2004e). It is not clear how far a plurality of provider is valued as a means of promoting choice, or whether it is mainly a way of mitigating the failure of mainstream services to provide what is needed for BME older people.

Making choices within services

For others, it seems more important to be able to make choices within services, for instance about mealtimes, bedtimes, balance of privacy and communal activities (Challiner 2000, Dewar, O'May et al). This was recognised by service users in residential care as being a case of balancing their needs with the institution (Dewar, O'May et al).

When older people were receiving care in their own homes the issue of choice was linked with control over what tasks the paid carers undertook (Dewar, O'May et al), and a suggestion that they may like some choice over who their paid carers are. A study which worked with older people to involve them in defining home care quality specifications (Raynes, Temple et al 2001b) found that provision of help to keep their home clean and help with small tasks such as changing light bulbs was highly valued, as were flexible services which can reflect current needs. Another study of service users' views on home care (Francis, Netten 2004) defined flexibility as a service where people could ask for help beyond their care plans. Respondents in that survey described experiences of inflexible services where care workers had refused to do tasks such as wiping the inside of a window, changing net curtains or helping with translation of official correspondence.

Choice about end of life

One study (Vandrela, Hampson 2002) discussed older people's perspectives on end of life decisions and when and how they would like to discuss these. This suggested that the right time was when the older person felt old enough, but not too ill, and when they accepted the reality of dying and/or had a personal experience with death and illness. In an age of medical advances, it was seen as important to discuss these issues.

This study found that people wished to talk to their doctors and family members about end of life issues, but their concerns about talking to medical professionals included ambivalence towards doctors and concerns about medical education and lack of professional standards in the medical profession.

Older people also wanted to talk to family members but were concerned about the family's involvement in making these decisions, which were seen as hard to take if there had been no communication about their wishes prior to being incapacitated. Living wills were seen as an important tool and effective means of communication.

Independence

Independence and remaining independent for as long as possible is a key theme in the literature. Independence is valued highly by older people (Henwood, Waddington 1998b, Hayden, Boaz et al 1999).

What does independence mean?
Independence means different things to different people and in different settings (Fisk, Abbot 1998, Hayden, Boaz et al 1999, Audit Commission 2004). A study which was particularly focused on exploring the meaning of independence to older people in various settings (Fisk, Abbot 1998) found the following themes dominant when older people talked about independence:

- The importance of deciding things for yourself
- The importance of money
- Limitations brought about by illness and family
- The desire to receive necessary help without becoming a burden
- The developing of strategies for mitigating loss and decline associated with aging.

Older people living in their own homes tend to view independence in terms of physical health and mobility and to perceive a potential move into residential care as a loss of independence (Hayden, Boaz et al 1999, Clark, Dyer et al 1998, Fisk, Abbot 1998). However, when older people were in residential care they were often able to find a way of expressing their independence, usually through exercising choice, for example about food and meal times, within that setting (Fisk, Abbot 1998, Hayden, Boaz et al 1999, Boyle 2004).

One study (Boyle 2004) found that older people living in institutions perceived themselves to have greater freedom to take their own decisions than older people receiving domiciliary care. Indeed, living at home did not mean that people could always make their own decisions. However, living alone may facilitate a higher degree of autonomy when living at home.

Enabling independence
There are some very clear messages in the literature about the support older people want in order to facilitate their independence. Almost all of the studies in this area are conducted with older people living in the community.

Having a safe, clean, well maintained and comfortable home was critical to maintaining independence (Hayden, Boaz et al 1999, Audit Commission 2004, Clark, Dyer et al 1998, Henwood, Waddington 1998b). Another study explored the high value of low level "preventative" services (Clark, Dyer et al 1998) and found them to be inextricably linked

with enabling older people's independence which in turn was dependent on remaining in their own homes, In this study older people were noted to refer to these kind of services as "help" not "care", reflecting their desire not to be seen as dependent. A further study found that most older people felt that if they could have more appropriate home help services, targeted to their individual needs, and practical assistance in maintaining the home and garden, they could remain living in their own homes indefinitely (Hayden, Boaz et al 1999). Aids and adaptations were also found to promote independence (Raynes, Temple et al 2001b).

Getting "out and about" was found to be another important facilitator of independence in a recent Audit Commission study (Audit Commission 2004). A study of people living in their own homes (Raynes, Temple et al 2001b) found that older people saw good safe transport as important in promoting their independence A further study (Hayden, Boaz et al 1999) found the inadequacy of public transport was considered by many older people to be a key obstacle to living an independent life.

These two studies also found that older people aspired to active social participation in order to maintain independence, for example in employment, learning and volunteering (Hayden, Boaz et al 1999) and as part of support networks (Audit Commission 2004).

As noted above, access to information was also found to be an important underpinning to independence in these studies and others (Hayden, Boaz et al 1999, Audit Commission 2004, Henwood, Waddington 1998b).

Having sufficient income is clearly important for older people's independence. This includes access to benefits and advice about benefits, and help with house maintenance (Hayden, Boaz et al 1999, Audit Commission 2004).

One study found that maintaining a healthy mind and body was the key to remaining independent as long as possible for many older people (Henwood, Waddington 1998b). This finding was reflected in another study (Hayden, Boaz et al 1999) where independence was defined within a physical context as being able to look after oneself on a daily basis without the need to resort any assistance from others. However, participants in this study who were less healthy and used the support of care services could still perceive themselves as independent in that the services enabled them to maintain their physical independence by enabling them to remain in their own homes.

Not being a burden

One study (of mixed age groups from 40 – 80 years) found a strong resistance to the idea of being dependent on families for care (Henwood, Waddington 1998b) and people had no wish to be a "burden". At the same time people described how they had cared for their parents and how they would not want anyone else looking after them because "they're my mum and dad". It was reported that questions of family relationships and caring responsibilities raised complex and ambivalent emotions.

Communication

The importance of communication and the need for improvements in communication in order to raise the quality of services for older people is mentioned throughout the literature. However, it is not always clear what is meant by "communication" and it seems to have

different applications in various circumstances. There are two main issues relating to communication. These are:

- communication between older people and agencies or organisations that provide services to them
- communication between older people and the individual care staff.

Communication between older people and care agencies

This is a major area of concern. Some communication issues relate to getting initial access to services (see discussion above), but there are also issues about the quality of ongoing communication between older people and their care providers. The literature consistently reports concerns by older people about communication on the timing of home carers' visits or changes in the timing or the carer. One study in Harrow (LB Harrow 2004) found a relatively high number of service users did not know the name of the agency providing their care worker. Also older people might be told they were having a different carer, but not their name (Raynes, Temple et al 2001b, Cooney 2000a, Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004, Francis, Netten 2004, LB Harrow 2004, Macauley 1998). There was also a lack of clarity about what tasks older people could expect the paid carer to carry out (Raynes, Temple et al 2001b).

Communication between older people and individual care staff

This was the other main concern to older people. One study compared the effect of interventions to improve communication between professionals with the effect of interventions designed to improve communication between older people and their individual care staff (Levin, Iliffe et al 2002). The study found the latter to be much more related to client satisfaction with services.

Communication with care staff is important to older people both for the information that is conveyed and for the quality of the relationship between the person and their paid carer. Older people want to have communication on the tasks to be carried out and issues that are troubling them (Cooney 2000a). They also want to have day to day things explained to them, for instance the change from their shopping (Cooney 2000a), how to fill in a form (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004). Finally, as noted above, one study suggested that older people would like to be able to talk with health and social care staff about end of life issues and decisions (Vandrela, Hampton 2002).

There was concern about the lack of communication from some paid carers, which seemed for older people to be compounded with a lack of respect for them (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004).

Some people reported that they did not always understand their carer (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004). This is a particular issue for BME service users, but does not apply solely to them. One study reported that communication had a different meaning to some minority ethnic service users and their informal carers; that it was important that care workers could speak their own language (Francis, Netten 2004).

User and carer involvement

Being listened to by staff and service providers and having their views acted on is an important aspect of social and public participation for older people and so intrinsic to their quality of life. They want to be involved in monitoring the quality of services (Hayden, Boaz et al 1999). At a "listening event" in North London BME elders suggested the establishment of an independent monitoring group into which they could feed their views and ideas (Age Concern England, undated).

Continuity of care

A user satisfaction study of home support services in Newham found that the most frequent comment from older people was that they wanted the same home support worker, who was friendly and caring and good at their job (Cooney 2000a). The desire for continuity of care runs through the literature, most usually expressed as having the same carer visiting their home.

The main reasons given by older people for wanting continuity of carer are to facilitate individualised care, to safeguard their security and sense of safety, and to facilitate friendship.

Individualised care
Older people often suggest that they receive better quality care, more individualised to their needs if the person providing the care knows them well (Dewar, O'May et al 2001, Walker, Radford 2000, Cooney 2000a). One study found that this applied in both home care and residential settings (Dewar, O'May et al).

Safety
For older people living in the community, concern about safety was also a reason for wanting to know their carer (Cooney 2000a, Dewar, O'May et al).

Friendship
A survey of home care service users in Newham (Cooney 2000a) highlighted the value older people placed on having a trusting and friendly relationship with their carer and some saw their support worker as "part of the family".

Food

Food is an issue about which older people frequently comment when asked for their views on care services. On the whole the literature suggests that the quality of food provision within care services, whether people live at home or in residential care is an important indicator for them of the quality of a service. One specific study which aimed to define user centred outcomes for care (Netten, Ryan et al 2002) found that older people generally ranked food behind personal care, social participation and control over daily living in terms of importance. People aged over 85 years, however, were more concerned about food and less concerned about social contact, and people with disabilities ranked food the highest. One study of older people with dementia in London (Redfern, Norman et al 2002) found that they were sometimes less concerned about food and more concerned about cleanliness, though food and feeding were often the focus of the day.

A Best Value study of residential care in Newham (Darcy 2001) found persistent complaints about food and catering both in terms of quantity and quality, though food does not appear specifically as a Best Value performance indicator.

The provision of food is an area where individual or cultural preferences can accommodated or not. Food is often particularly mentioned as a quality indicator for Black and minority ethnic older people, possibly because it is an area where they often do not have their needs met. Food is also a quality of life issue and much more than just fuel. The importance of mealtimes and the circumstances in which people eat are also mentioned.

Further discussion of older people's experiences of food provision can be found in the support in the community and residential care sections.

Continence management

Having good management of continence is a quality of life issue, though this is not often an issue about which older people are asked. One study (Peters, Horrocks et al 2004) found that the greatest single influence on use of services for older people was being asked whether there were continence problems by a health professional. The authors suggest that by asking older people specifically about urinary leakage they could reduce inequalities in use of services.

HOUSING AND ENVIRONMENT

Housing

For many older people the links between suitable housing and suitable care are inextricably linked. This can be relevant to all aspects of housing, including location, type and quality of accommodation and where it is located. This section looks at what older people have said about housing and allied issues; sheltered housing is specifically discussed later in the report as an aspect of support in the community.

Housing is a concern of older people

A seminar held in Cardiff reports older people as being concerned about problems of high rise living, isolation and no sense of community (PRIAE 2000). A report of older people's priorities for health and social care (HOPe Group 2000) discusses the location of services and design of buildings, which, it says, should be designed with older people in mind.

A meeting of an older people's assembly at the Greater London Authority (Mayor of London 2003) warned that older people are disproportionately represented in the groups that do not have central heating in the London areas and this linked to poor health amongst older people. They also stated that homelessness amongst older people is a real problem.

Nor is the picture uniform across all ethnic groups. Ethnic minorities are more likely to live in older, unmodernised, inner city housing which is lacking in central heating and other household amenities, such as gardens and washing machines. White older people have the largest percentage of outright owner occupation, while older Indians are more likely to be still buying their property. Renting from the local authority is particularly important for older Bangladeshi and Black African older people (Age Concern 2000).

Better housing for older people - what is needed?

Fora in Glasgow and Birmingham (Fisk 1999) described a number of parameters for housing for older people:

- Keep it local – so that care and housing are available for older people in their local communities
- Using universal designs – dwellings should be designed in accordance with universal principles taking account of the example set by "lifetime homes"
- Services should be flexible to meet the changing needs of older people and operate within new and more responsive funding networks
- Information and the customer ethos – an ethos is required which acknowledges the rights of older people as customers able to make informed decisions and choices
- Respecting diversity – considering individual needs requires recognition of diversity of older people
- Promoting independent living – dwelling designs should promote independent living, rehabilitation and the engagement of older people in a and contribute broad community context
- Promoting integrated environments – inclusion requires older people to live within environments comprising people of all ages
- Rejecting residential care – dwellings build to lifetime homes standards should replace outdated and ageist dwelling forms such as residential homes

- Offering security – housing for older people must be secure and could be effected by closer community integration and new technologies
- Reaching higher standards – the desire for bungalow style dwellings and higher space standards must be recognised and responded to.
- Giving speedy responses – location of support services is less important than their ability to respond swiftly and sensitively to individual needs.

The report also raised related issues, including:

- Age audits and strategic framework – age audits should be undertaken to examine, and where necessary change, relevant housing, welfare and planning frameworks
- Community alarm services – should be repositioned in order to realise their potential in relation to social welfare and healthcare agendas
- Housing standards - further improvements should be considered
- Prefabricated housing – the government should promote further investigation into the potential of new forms of prefabricated housing.
- Care and repair - will remain important and additional resources should be assigned to enable their extension
- Equity release and flexible tenure – opportunities should be further explored.

The report also expressed its opposition to traditional sheltered housing and to residential care.

Other reports make specific suggestions about housing. For example, a conference of Chinese older people (Chau, Yu et al 2002) suggested that "self purchased" Chinese older people's housing schemes should be introduced to enable Chinese older people to live together and keep in touch with each other. Also, they suggested that application procedures for older people's housing services should be simplified and made more transparent.

To move or not to move

Older people vary in whether, and when, they wish to move into more "suitable" accommodation. One study in urban areas of Scotland (MacDonald 1999) found that even when they lived on upper floors of flats and tenements without lifts, older people were on the whole prepared to suffer the inconvenience of negotiating stairs (or even not going out) rather than move away from neighbours.

Older people living in various types of housing in Plymouth, Birmingham and London (Thomas Pocklington Trust 2002) were studied and those who were losing their sight wanted to stay in their home as it was more familiar.

A submission by Age Concern (Age Concern 1998) reported difficulties of older people in getting moved into appropriate accommodation when they were assessed as needing it.

Joining up services

Several reports make explicit links between aspects of health and housing. A literature review (Boaz, Hayden et al 1999) noted that as people get older their housing needs become increasingly intertwined with their health and care needs. Older people want to stay in their homes for as long as possible, but the infrastructure needed to support this choice is often inadequate. Older people identify a need for flexible home care, which puts the needs of the older person at the centre of a care package. Other services, such as a good transport system, are also seen to be important to people living in their own homes.

A report from Newham (Newham HIMP 2003) says that intermediate care should link better with housing. In Barking and Dagenham, Havering, Redbridge and Waltham Forest older people felt that housing and social services agencies should communicate more effectively (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004).

Safety and security

The literature provides several examples of older people's concerns about safety and security, in their home environment, and beyond. These concerns are an integral part of what matters to older people in their homes and when they go out.

Feeling safe and secure

Older people want to feel safe and secure in their neighbourhoods (Bowling, Gabriel et al 2002) and also in their own homes. Indeed, one study acknowledged that feeling safe and cared about were amongst the benefits of home care (Clark, Dyer et al 1998). It also noted that for women in particular there was considerable concern about having unknown men in their homes.

Some frail older people and those with mental health problems fear going out alone (Age Concern Barking and Dagenham 2000).

A sense of safety and security is also valued by some residents in extraCare housing (Bartholomeu 1999) where an entry phone and a continuous staff presence were features. Some studies also show that residential care is valued for safety and security aspects (Moriarty, Webb 2000, Challiner 2000).

Racial harassment

BME communities may experience additional safety and security concerns, such as the experience of and fear of racial abuse and racial harassment. A Social Services Inspectorate report found that policies and procedures for the protection of older people were mostly generic and did not specifically address areas like racial abuse and harassment (SSI 1998).

Equipment, aids and adaptations

Wherever older people live, they may, at some stage, need aids, equipment or adaptations to enable them to live as safely and as independently as possible. As noted above, the provision of aids and adaptations is an important dimension of quality for older people. A large study in Manchester (Raynes, Temple et al 2001a) showed that older people saw the provision of aids and adaptations to promote independence as aspects of quality. In Lambeth, almost 48% of older residents surveyed saw well maintained equipment and facilities as an aspect of service that they rated as very important (MORI 2002). However, the literature has several examples of how this service provision does not always work as it should.

Problems in accessing equipment, aids and adaptations

Unfortunately, most of the literature references on equipment, aids and adaptations draw attention to continuing limitations and shortcomings in the provision of such services. In Croydon, there were some problems in the Elderly Hospital at Home Team in accessing

equipment at weekends (Croydon CHC 2002a). A Barnet CHC discharge survey found that a significant minority of people had problems getting aids and adaptations they needed, or experienced delays with these.(Guest 1999). Barnet CHC also noted that there was limited access to wheelchairs in nursing and residential homes in their area (Barnet CHC 2001b).

Positive suggestions

In order to improve services, older people in Wandsworth supported the borough's "equipment shop" (Wandsworth Borough Council 2000). In outer north-east London, older people suggested that adaptations such as stair lifts could be recycled when people leave council housing (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004).

SUPPORT IN THE COMMUNITY

A large proportion of the literature is about older people living in community settings and the support services that enable them to stay in their own homes.

Home care

One study (Patmore 2001) finds great variety in the kinds of issues people raise when asked about their preferences for home care. These seem to relate to their individual experiences of the care they are receiving and the particular strengths and weaknesses of care in different geographical areas. Another study found that performance of home care services was largely determined by people at a low level in the organisation - home care staff and organisers; (Henwood, Waddington 2002) and a further study (Help the Aged 2002) found that users' satisfaction was defined by their individual experience with an individual care worker.

Consistently, the main concerns that older people express about home care are a desire to have control over their care; to have continuity, reliability and consistency; and for the care services to be sufficiently flexible to be able to meet individual needs. A major concern is the lack of, or perceived inability to access, low level services such as housework and gardening.

What determines use of home care services?
A study of service users in one city (location not known) (Stoddart, Whitley et al 2002) found that greater use of home care services was associated with:

- Older people with poor eyesight
- Older people who had falls
- Poor foot health
- Hearing problems
- Women with urinary incontinence
- Smaller social networks
- Poor emotional support
- Poor mental health.

One study (Roberts 2001) found that some older people declined help that was offered for reasons including the availability of other sources of help (private or informal), wishing to retain independence or a feeling that the service offered was unnecessary.

A study looking at outcomes of integrating health and social care in two London boroughs (Levin, Iliffe et al 2002) found that the number of home care hours provided was the second most important factor contributing to keeping people at home.

What do older people want?
A major study to examine what older people wanted from home care services (Henwood, Lewis et al 1998) found that what service users valued most was:

- Reliability of staff
- Continuity of care and of individual home carers
- Kindness and understanding shown by care workers
- Cheerfulness and general manner of care workers
- Competence in undertaking specific tasks
- The flexibility to respond to changing needs or requirements

- Knowledge and experience of the needs and wishes of the service user and their carers.

These findings are reflected in another study funded by the Joseph Rowntree Foundation three years later (Raynes, Temple et al 2001a). In addition, this study found that older people particularly valued help with small tasks such a changing a light bulb, and that, for those under 80 years, the provision of company was an important part of the service. Those over 80 years stressed the value of having something to occupy their minds, but wanted "robots" to do their domestic tasks for them.

Similarly, a recent small scale study for the Department of Health (Francis, Netten 2004) found the following aspects of quality important for users of home care services:

- Reliability
- Flexibility
- Continuity
- Communication
- Staff attitudes
- Skills and knowledge.

A recent Department of Health survey (Department of Health 2003) found that only 51% of respondents in outer London were extremely or very satisfied with the help they received from social services in their home, compared with 55% in inner London and 57% nationally.

The high value of low level preventative services

A Help the Aged report (HOPe Group 2000) of older people's priorities stated that home care currently excludes large numbers of older people who need a bit of support to remain independent. Many older people who do not need personal care do need help with a variety of practical tasks. The participants in one study of both actual and potential service users expressed concerns that services on offer "don't cover what people really need" (Henwood, Waddington 1998b). Such needs included help with housework and with household and gardening tasks. A study in the South of England (Clark, Dyer et al 1998) found remarkable consistency in what older people said about the value of help with housework, gardening, house repairs and maintenance, security, and laundry. Older people were happy to accept help with tasks they could no longer manage for themselves provided it did not impinge on those areas they could still manage. The benefits of having help with these tasks included feeling safe and being cared about. The study also found some gender differences in that men tended to see help with housework as functional, whereas for older women the appearance of their homes was evidence of their ability to maintain acceptable standards and linked to their identities as competent members of their communities.

An account by one woman aged 87 years (cited in Atkin 2002) sums up the importance of getting help with housework:

> *The council said they no longer provided help in the home! The only help I would get in future would be personal. I could have half an hour for a bath and an hour for a hair wash per week.*
>
> *Most people of my age are used to living in a clean home. Now we must sit like Miss Haversham, watching the debris mount up. Even worse, for people with no relatives or good neighbours, no more shopping will be done.*

I was told that if I needed help with housework, there were adverts in the newspaper. I didn't want strangers in my home so I was given a list of agencies. Then I read the small print... the council gives no undertaking as to the agencies' suitability.

Reliability, security and continuity

Continuity is defined in one study (Francis, Netten 2004) as having of a regular carer or team of regular carers. It was found not to be important to all those interviewed, though more important to those with visual impairment or dementia, or where children might have to answer the door. As noted above, security is a key concern for older people and is often mentioned in relation to home care. Older people want to know who is coming into their homes (Clark, Dyer et al 1998).

Routine, control and continuity in personal and household care is particularly important to carers and people with dementia (Age Concern 2000). Disruptions to routine or perceived lack of timekeeping were viewed negatively by carers and were perceived as disruptive behaviour by outsiders whose involvement was meant to support family care giving.

Flexibility

The need for services to be flexible is stressed throughout the literature (Dewar, O'May et al 2001, Walker, Radford 2000, Francis, Netten 2004). In one study (Francis, Netten 2004) older people defined flexibility as a service where they could ask for help beyond their care plans. It was found most important to those living alone.

Flexibility usually relates to the kinds of tasks home carers carry out, and the control that older people have over these. One small study (Roberts 2001) found that the perception that home helps could not do the kind of tasks that people wanted led to older people refusing this service (and sometimes paying privately). However when people had actually received statutory home helps they found that they were often more flexible in their duties than older people had previously perceived.

Flexibility is largely about meeting individual needs. A report of a major study on improving home care quality (Patmore 2001) stated that all findings pointed to the need for an individual-centred approach as people's preferences vary. This study recommended face to face meetings for gathering individual preferences and suggests that as older people's health, social networks and support change over the years, time should be invested in discussion with older people and family carers about changing preferences.

Another study of older people's priorities for improvement found that service users were most concerned that paid carers knew the person they were caring for in order that they would understand their needs and provide an individual service, however it found that older people felt they had little control over who they were allotted as a home help and what sort of care they would provide (Dewar, O'May et al 2001).

Training and support of home care workers

One study (Roberts 2001) found that people were much more likely to accept health care than social care offered to them as it is assumed that in the health field there were experts who knew best. On the whole, however, the literature suggests that older people value the skills that home care workers bring and that they particularly value positive attitudes in their carers,

such as respect, friendliness, cheerfulness, being obliging and understanding rather than the more functional aspects that training might focus on.

A recent study for the Department of Health found that informal carers were less concerned with skills identified as important by service users (for example moving and handling, personal care tasks or domestic help) and more with home carers' initiative and professional awareness (Francis, Netten 2004). Many service users did not judge their care workers' knowledge and skills in the way they would be commonly defined by training methods and standards: if their care workers cared, they were good care workers.

A report of a Help the Aged conference found that older people were concerned that poor pay and status of home care workers undermined good care (Help the Aged 2001a). Another study found that the low priority given to domestic help by social service departments did not accord with how older people, (and women in particular), saw it. They had a high regard for the competencies and skills involved in housework. "The *work* of housework was at least as important as the *care* of personal care (Clark, Dyer et al 1998).

Personal care

There is little in the literature specifically relating to personal care, (though some of the points made above on continuity of care are often made by those receiving personal care). As this was a study of older people's views on care services, the lack of discussion of personal care probably reflects their own priorities, and the fact that the older people may be reluctant to talk about the details of personal care. One study of older people receiving bathing services (in London and the South Coast) found that people preferred help with bathing to be offered by a bathing assistant and not by their home care worker (Twigg J). Another study, however, found some users wanted home helps to take on personal care tasks (Dewar, O'May et al).

Black and minority ethnic older people's experience of home care

In a national survey only 44% of BME respondents said that they were extremely or very satisfied with the services they received in their home compared to 58% of white respondents (Department of Health 2003). On the whole the literature suggests that the concerns that BME older people have about home care are similar to those of all older people; continuity of care, wanting to get help with household tasks. There are some specific issues relating to race, however.

A report of a seminar in London suggested that people had experienced racial discrimination in care and assessments (Patel 2001). Having home care assistants who speak a person's language is very important to minority ethnic service users (Francis, Netten 2004). At a consultation event in Tower Hamlets a Vietnamese woman said that the most important ability she valued in a home care worker was that they could communicate in her language, this was echoed by Chinese people at the event (Begum, Miah 2004a). Another consultation in Tower Hamlets found that people valued the home care service and felt that social services should not assume it was the family's duty to take on the caring role (Begum, Miah 2004b). The language barriers meant that information about services available and people's right to them were often compromised.

Food

As noted above, the quality of food and the way it is provided are important concerns to older people. A study conducted by MORI of Lambeth's provision for older people in the borough

found that the meals services attracted some of the highest "very good" ratings and highest "very poor" ratings (MORI 2002).

A study of user satisfaction with Newham Social Services' meals in the home service (Regan 2001a) found that meals were not always delivered hot enough and nearly a quarter of meals arrived outside the target delivery time of 12 – 2pm. Less than a quarter of those receiving frozen meals always received what they had ordered. Finally 10% of white British people were dissatisfied with the service compared with 25% of the other respondents.

A report from a recent consultation with BME communities in Tower Hamlets (Begum, Miah 2004b) found that meals on wheels services were not popular amongst the Bangladeshi community for a number of reasons, including the taste, the lack of halal meat and other issues around the preparation of the food. An inspection conducted by the SSI in 1998 of community care services for Black and minority ethic older people across England, including two London boroughs, (SSI 1998) found that basic services like meals on wheels were provided in an inappropriate manner. At a seminar of BME people and organisations in London it was reported that Chinese meals were not available from the meals on wheels services in many London boroughs.

In the Tower Hamlets consultation (Begum, Miah 2004b) BME older people living at home said they would prefer meals cooked by an organisation they knew and trusted or to have home carers assisting them with the cooking and taking them shopping to choose their own food. At a conference on health and social care priorities for older Chinese people in London (Help the Aged 2001b) there were complaints that care workers could not prepare Chinese meals. This was seen as an example of how domiciliary care services failed to deliver packages tailored to their individual needs.

In a study of older people with dementia (Moriarty, Webb 2000) traditional meals services were criticised by carers due to lack of choice, quality and presentation and the inability to meet all dietary needs and preferences. The timing of delivery of meals and the fact that delivery staff were not able to stay and ensure the food was eaten were also cited as problems. Help with meal preparation in the older person's home was also preferred by the carers of this group of people, and particularly appreciated when the home care staff stayed to ensure that the person ate the food.

Home care services in London boroughs

There are comments relating to home care services in a large number of the London borough-based reports reviewed. These reports are from a number of sources; some are reviews or surveys, (including Best Value reviews), conducted in-house or commissioned out to a consultancy or local voluntary sector agency (for example Age Concern); some are joint SSI / Audit commission reviews; and some are CSCI reviews.

As noted above it is usually not possible to disaggregate the findings and clearly discern what were the views of older people themselves, and their carers, though in places it is clearly stated that these are the views of older people. Given these limitations, the following issues are raised in the reviews and surveys.

Individual, person-centred approach

An recent CSCI inspection in Havering (CSCI 2004d) of services for older people found that services were considered traditional and lacked an individual person-centred approach. A

recent CSCI inspection in Hillingdon (2004c) of older people's services reported that services were traditional, lacking focus on outcomes for the service user, and a joint review report of Bromley social services (SSI / Audit Commission 2001b) stated that assessments needed to focus on the needs of the person, not just the immediate problem.

In two reports, however, the individual approach was commended. A fundamental review of services for older people in Croydon (LB Croydon 1999) found a key strength of the home care service was that individual service plans were flexible to the needs of the individual, though they did not always have sufficient staff capacity to deliver the care plans. A survey of user satisfaction with Newham's home support services (Regan 2001b) found that 86% of users said that their home support worker always or usually took notice of how they liked things done.

Numbers of older people placed in residential and nursing care not decreasing
The CSCI report of Havering's older people services (CSCI 2004d) found that the number of older people being placed in residential and nursing care was increasing. The Bromley joint review (SSI / Audit Commission 2001b) reported that community care services need to focus more on enabling independence and supporting people to stay in their own homes. The CSCI inspection in Hillingdon (2004c) said that the older people's services were reliant on residential and nursing care.

Quality and quantity of support for older people in their own homes
The Havering CSCI report (CSCI 2004d) found that support for people in their own homes was not satisfactory. A joint review of Croydon's social services (SSI / Audit Commission 2000b) found that services to older people needed to be better targeted to enable packages of care to support people in their home. A joint review in Redbridge (SSI / Audit Commission 2000c) recommended that the organisation of home care should be reviewed. A report of a joint review in Hounslow (CSCI 2004e) found that most older people and carers were satisfied with the quality of the services they received, but there was a need to develop capacity and specialist provision in domiciliary care. A joint review in Ealing (SSI / Audit Commission 2003b) found relatively high levels of service for older people, (but gaps in the level of support available to other vulnerable adults).

A borough wide survey of older people conducted as part of a Best Value review of older people's services in Hounslow (LB Hounslow 2003) found that 62% did not receive help or support to remain in their own homes and 39% thought that they would need more help in the future, mainly in the home and with gardening. A survey of user satisfaction in Newham (Regan 2001b) found that while the vast majority of older people were satisfied with the quality of care they received, one in ten were not. A Best Value review in Wandsworth (Wandsworth Borough Council 2000) found the quality of home care was a matter of chance and dependent on the individual carer, not necessarily the organisation for which they worked.

Range of services and choice offered to facilitate independence
This is particularly an issue focused on by joint reviews. A report of a review in Lewisham in 2003 stated that there had been significant achievements in promoting independence in adult services notably in older people's services (SSI / Audit Commission 2003a). The Hounslow joint review in 2004 (CSCI 2004e) found the range of services was increasing and offering more choice for older people. A joint review in Greenwich in 2002 (SSI / Audit Commission 2002b) found that although services for older people in general have not

progressed as far as other services, increasing numbers of older people are supported intensively at home. A joint review of Hillingdon social services in 2003 (SSI / Audit Commission 2003d) found that they needed to develop a better range and better quality services for older people and those who care for them.

Concerns about quality of independent sector home care
A workshop held by the HIMP forum for older people in Newham in 2003 (Newham HIMP 2003) reported that the number of home support providers in the Borough were too many and that there was a need to reduce so that it was possible to monitor them. A CSCI inspection in Hounslow found concerns about the quality of independent sector home care (CSCI 2004e). A report of a CSCI inspection in Hillingdon in 2004 (2004c) found there had been problems with the late arrivals of home carers, particularly from external agencies, though these were being addressed. A Best Value study in Camden in 2000 (Dalley, Hadley 2000) found much of the dissatisfaction expressed by older people receiving home care related to services provided through agencies. An analysis of a survey of user satisfaction in Newham (Regan 2001b) compared in-house and external providers of home care and found the in-house services significantly better on a number of important quality indicators; including the percentage of service users saying they were treated with respect, workers staying for the correct amount of time, the timekeeping of workers and their reliability, the percentage of service users saying they could talk to their home support worker about things that were worrying them, the percentage of service users saying that their home support worker cared about them as a person and the overall quality of care.

Continuity of carer, consistency of timing and notification about changes
The MORI survey of older people's services in Lambeth (MORI 2002) found that older people wanted more consistency in the service and regularity of personnel. A Best Value study in Camden (Dalley, Hadley 2000) found that older people did not like care workers turning up too early or when not expected. And a Best Value review of services for older people in Wandsworth (Wandsworth Borough Council 2000) found concerns from users about keeping the same home carers and concerns abut their timekeeping. A customer satisfaction survey of home care in Harrow (LB Harrow 2004) found the following concerns:

- The relatively high number of service users (34 out of 120) who do not know the name of the agency providing their care worker
- High number reporting that they rarely have the same carer at weekends
- High number who say carer rarely comes on time at weekends
- High number reporting that they are rarely informed if their care worker is going to be more than 30 minutes late
- High number who report that they are rarely informed if a different care worker from their usual one is being sent (65%).

A survey of user satisfaction with home support services in Newham (Regan 2001b) found:

- One in eight people did not know when their help was supposed to arrive, and a similar number who did know could not say when they usually arrived because it varied too much
- 86% were satisfied with their worker's timekeeping
- One in five said their home care support had not turned up at least once in the last month
- Over a third said they had not been told when a replacement worker was coming to see them.

A Best Value review of home care services in Hillingdon (LB Hillingdon 2000) found that service users highlighted a range of problems in reliability, choice of timing and advance notice of changes. Though a recent CSCI inspection report found that the problems with late arrival of home carers, particularly from external agencies, were being addressed.

Need to develop "preventative" services to meet low level need
The CSCI inspection of Hounslow social care services for older people (CSCI 2004e) found that there was a need to develop a range of community based options for older people to meet low levels of need. A report for Lambeth council by MORI on older people's services in the borough (MORI 2002) found that older people wanted greater flexibility in the home help service, for instance doing more menial tasks such as bathing and offering more outings and help with shopping. A Best Value review of assessment and care management in Hillingdon in 2001 (LB Hillingdon 2001) found that eligibility criteria in home care was perceived by older people to exclude housework and cleaning which impacts on quality of life. A joint review of Hackney social services in 2003 (SSI / Audit Commission 2003c) found that direct care services for people with high levels of need are of good quality and services are reaching the most vulnerable, but broader preventative services need development.

Delays between referral, assessment and provision
A Best Value review of Hillingdon's assessment and care management (LB Hillingdon 2001) found concern at waiting lists for assessments and lack of clarity on the process. A recent CSCI inspection report of Havering's services for older people (CSCI 2004d) found lengthy delays between referral, assessment and provision of services. In addition a number of joint reviews raised concerns about delays:

- Waiting times for some assessments and services are unacceptably long - Ealing (SSI / Audit Commission 2003b)
- In adult services high numbers of lower priority cases waiting for assessment or reassessment – Lewisham (SSI / Audit Commission 2003a)
- Initial assessment for adults and older people could be streamlined – Waltham Forest (SSI / Audit Commission 2002c)
- Long waits for assessments and inconsistent initial responses to people needing services – Greenwich (SSI / Audit Commission 2002b).

A joint review in Hackney (SSI / Audit Commission 2003c) found that waiting times had reduced.

The fundamental service review in Croydon (LB Croydon 1999) found that the in-house home care service had good access for urgent community referrals.

Black and Minority Ethnic service users
The quality or quantity of services for BME service users are frequently mentioned in reports of joint reviews, usually to highlight poor provision, but there is not sufficient to detail to discern whether these comments apply to home care services for older people.

Some of the other borough based reports highlight good or poor provision for elderly BME home care users. A report to Wandsworth Council in 2000 on their best value review of older people's services (Wandsworth Borough Council 2000) found that concern was expressed about the disproportionate difficulty for BME people in accessing services and that the cultural implications of the caring role in the Asian community need to be better understood in order to provide appropriate services. It was reported, however, that specialist provider

projects for BME groups were very much appreciated. The CSCI report of Hounslow's older people's services also found some highly regarded culturally specific services, some using direct payments (CSCI 2004e).

A number of reports find poor home care provision for BME service users:

- Lack of appropriate provision for members of black and ethnic minority communities – Croydon (LB Croydon 1999)
- Problems in providing culturally sensitive services – Hillingdon (LB Hillingdon 2000)
- Concern at low number of service users who were asked to identify specific cultural needs – Harrow (LB Harrow 2004).

Sheltered housing

The literature on older people and sheltered housing confirms that, in general terms, older people regard sheltered housing as a way of feeling secure, while retaining as much independence as possible. It is seen as a usually preferable alternative to residential care (Newham HIMP 2003, LB Hounslow 2003). While sheltered housing is often seen as helping older people to feel secure, this may be less easy to ensure where there are "dispersed properties" as opposed to sheltered housing complexes (Housing Best Value Inspection Service 2001). The literature also looks at awareness of, and need for, sheltered accommodation, its quality and older people's satisfaction with it.

Awareness of sheltered housing

A study of the housing and social care needs of older people from BME communities in Derby (Steele 1999) showed that nearly 2/3 of respondents had heard of sheltered housing. Those who were least likely to know about it were from the Asian community. 96% of Chinese and 87% of Black Caribbean people had heard of it. Those aged 75+ were more likely to have heard of it than the younger age groups in the sample.

There was a low level of perceived benefits of sheltered housing. Four out of ten did not know of any and one fifth felt there were no benefits. Of the remaining comments, most common was that sheltered housing provided a caring environment for older people without family to care for them, (17.3%). Nearly 4% mentioned someone being on call, 2.3% mentioned that respondents retained their independence and 2.3% felt sheltered housing was "better housing". The most common perceived disadvantage was moving away from family and friends (17.5%) but nearly half did not know about disadvantages.

Over twenty per cent would consider moving to sheltered housing and 26.7% were undecided. The Chinese community was most willing to consider sheltered housing (92%), in contrast to only 11% of Indians, 10.9% of Pakistanis and 6.3% of Bangladeshis. Those who would not consider sheltered housing were asked if a BME sheltered housing scheme sensitive to the needs of a particular community would change their minds. Only 12 respondents (3.2%) said it would and 8 of these were from the Pakistani community.

Location was very important to almost all. The issue of residents being from the same community was very important to 61.5% of Indian respondents and 95.7% of Chinese, in contrast to 16.7% of Black African and 8.1% of Black Caribbean people.

Older people's experiences of sheltered housing

Interviews with residents of Abbeyfield Society Housing in Scotland, Wales, the south east and North Thames (Kellaher, Schroeder 1998) showed that, in addition to concerns about their future care, their main observations were about day to day organisation and management and the tension between independence and companionship. On the former, the impact of the housekeeper was very important. Also, the level of openness in organisational matters was important to many residents, who wanted to understand how the house worked, what it cost and the "lines of command". This contributed to increased feelings of homeliness and security.

With regard to the independence and companionship tension, there was some tension. Residents came to Abbeyfield because of loneliness, but attitudes towards other residents could be ambivalent. Resident relationships tended to be akin to those of neighbours who lived near each other perforce, rather than chosen friends. Companionship was seen as relating more to outside relationships. Residents valued their own rooms but also spoke positively of shared spaces (for example living room and dining room). Having one's own key and the freedom to come and go was valued by all. This was also found in another study (Bartholomeu 1999).

Support in sheltered housing

A study by Hanover Housing Group (Bartholomeu 1999) interviewed 165 residents in seven areas of extraCare provision, including one London area (Merton). It found that location was important as residents liked to feel part of the wider community and have access to facilities. It also found that extraCare supplied a welcome sense of security, with an entry phone and a continuous staff presence. In general comments from residents in favour of extraCare stressed independence, security, the actual or potential support of the Estate Manager and care staff, the sense of security and the provision of decent midday meals. Less favourable comments focussed mainly on the availability of carers, with residents perceiving that staffing levels were at times too low to cope.

Very similar findings emerged in Camden (Dalley, Hadley 2000), where all residents were satisfied with their housing manager or "warden". Various means of checking on them was used (buzzing, telephoning, calling in) and all were acceptable. The knowledge that a warden was there to provide security was one of the most commonly mentioned reasons for moving into sheltered housing. Security and friendship were also valued.

A study in Croydon (LB Croydon 1999) analysed services provided to older people by the social services department of the London Borough of Croydon. It focussed on people who received home care services, were tenants in Special Sheltered flats or were living in residential or nursing home care (or in some instances a combination of these). The identified strengths of the sheltered housing service – security, promotion of independence, social activities, support from staff etc all mirrored other studies. The weaknesses – in addition to identifying a need for more provision – were as follows:

- Need to be able to maintain people with higher dependency levels than currently offering - especially for the elderly mentally frail
- Only provide meals over a 5 day period
- Have few staff on duty at night for number of disturbances
- No assessment facility available to determine suitability of service for potential tenant

- No trial period facility for people to experience the reality of moving from their own home
- Some units are located such that it is not easy to travel by public transport to the shops.

A cross borough listening event in Barking and Dagenham, Havering, Redbridge and Waltham Forest (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004) noted that sheltered housing support from wardens was available during the daytime office hours, but many older people felt more vulnerable at night when access to services is more difficult. A similar point was made in Croydon (LB Croydon 1999).

In Slough (Housing Best Value Inspection Service 2001) the average number of visits that residents received was 3 per week.

There was no up to date information available on the services available to older people in supported housing and few older people knew that social activities were on offer from the supported housing service. Only 68% were satisfied with the Careline emergency alarm service (a large drop from three years previously) and there was a discrepancy between Careline's performance data of their service and what older people reported on their experiences.

Alternatives to sheltered housing

One study (Fisk 1999) advocated that resident wardens should be phased out and community based services be developed for people with support needs.

Day care

What is good about day care

The benefits of day care to older people and their carers are highlighted in a few reports. A Best Value inspection of day care services for older people in Bromley (SSI / Audit Commission 2001d) found that many service users valued the support they received and that most value was attached to the assistance day care services provided in breaking social isolation and enabling carers to have a break. A literature review of older people's views in Scotland (MacDonald 2004) found that the main benefit of day care as perceived by unpaid carers of older people with dementia was respite for themselves. A study of older people with dementia found that day care for service users greatly improved the value of life for carers and that some of the older people with dementia also liked day care. They cited social aspects and the change from being at home as benefits. A fundamental services review in Croydon of services for older people (LB Croydon 1999) identified the following strengths of local day care services:

- Allows people to live independently at home for a longer period
- Provides social activities and contact with peer group to avoid isolation
- Helps people to maintain independence and regain confidence in tasks of daily living
- Provides help with specific tasks such as bathing and provides meals
- Assists people to be introduced to communal living as preparation for when they may need to move into residential care or take a short break from home to relieve carers
- Provides support to carers.

What older people want from day care

A survey of the social and leisure activity aspirations of older people in Wandsworth (LB Wandsworth 2004) found that users of day care were varied, but tended to be over 75 years and without their own means of transport. They did not appear to have significantly greater health problems or be less active than others. One in four older people in Wandsworth were interested in finding out about day services, if they did not already use them, although there were mixed views on this kind of provision. Some people felt specific provision for older people was a good thing, whilst others made comments like "miserable" and "depressing". There was a sizeable minority of those over 75 years, however, who wanted to participate in activities only with other older people.

Research in the North of England (Cattan 2002) found that older people wanted activities tailored to their specific needs and many preferred a small task oriented group (for example cooking class) to sitting in a large group in a community centre. Older people wanted a variety of activities available within their local neighbourhood or within reasonable travelling distance.

Problems with access to day care services

An independent survey of older people in Croydon reported in their review (LB Croydon 1999) found that service users thought that day care services were not publicised sufficiently well. In most cases those who used such services had been referred by their doctor, rather than finding out about the service independently. A report of a seminar of BME older people in Wales (PRIAE 2000) found that several people were not aware of day care services.

As mentioned below, the cost of day care services is mentioned in two studies as a possible barrier to use (Age Concern Waltham Forest 2004c, HOPe Group 2000).

The Croydon inspection report (LB Croydon 1999) finds that there is a lack of access to culturally appropriate day services for members of BME communities. A consultation with older people in Barking and Dagenham found that BME groups wanted a separate day centre to enable "a sense of belonging". A study of Greek and Turkish speaking older people in Enfield (Yahioglu 2004) found a need for a day centre for BME communities there. Other groups found not to be catered for are:

- People with mobility difficulties – Croydon (LB Croydon 1999)
- Those who are doubly incontinent – Croydon (LB Croydon 1999)
- Older people with mental health problems – England (Audit Commission 2002a), Barking and Dagenham (Age Concern Barking and Dagenham 2000).

Transport to and from day centres is also an issue raised in a number of studies. This is reported in more detail below.

Transport

The value of transport for older people

As noted above, an Audit Commission report on independence and well being for older people (Audit Commission 2004) found that transport to enable older people to get out and about was one of the key factors in facilitating their independence. Another study on the aspirations of older people (Hayden, Boaz et al 1999) found the inadequacy of public transport to be a key obstacle to living an independent life. A further study in Manchester

(Raynes, Temple et al 2001a) found that older people saw good, safe transport as promoting independence and affected their attitudes to living in their homes. A Best Value review of services for older people (over 55 years) in Hounslow found that public transport was seen as the most important factor in contributing to quality of life (LB Hounslow 2003).

The Help the Aged HOPe group report (HOPe Group 2000) stated that transport was a major issue for older people and important both for accessing health and care services and for staying in control of your life. And a report by Croydon CHC (Croydon CHC 2002a) found that effective co-ordinated transport was crucial for older people in accessing health care.

Older people's experience of transport services

An Audit Commission review of Dial a Ride services in London (Audit Commission 2002b) found high levels of satisfaction for the punctuality of bus arrival and helpfulness and courtesy of drivers and booking service. However, the review found considerable dissatisfaction from users about:

- Geographical restrictions on journeys – usually only allowed to go two miles beyond their regional boundary;
- Limitations for service users arising from booking process – they were often not able to book for day and time they wanted;
- Problems getting through to booking service;
- Security and safety – safety belts not long enough, unclear methods for communication in event of an accident involving the driver
- Lack of outings and trip restrictions.

Consultation with older people in Barking and Dagenham, Havering, Redbridge and Waltham Forest found that Dial a Ride needs to be improved and needs more resources (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004). This consultation also found a need for bus stops near older people's venues.

A UK-wide study of older people's experiences (Hayden, Boaz et al 1999) found that bus stops were located too far from people's homes. This study also found that buses were viewed as unsafe and infrequent, bus stops were uncomfortable and bus drivers were insensitive to older people's needs.

Consultations with users of transport services to Newham's social services day centres (Craw 2001 and Collyer 2002) found a high level of satisfaction with the following service aspects:

- The kind of vehicle they travelled in
- Escorts were polite and courteous
- The length of their journey
- Being picked up at the designated time.

The sheer convenience of such a service which gets people out of the house was appreciated, but transport was seen by the service users as more than just a means to an end. It was noted that many people enjoyed the journeys due to the friendly atmosphere on board.

The main dislikes were:

- Lack of leg room
- Difficult access to the vehicles

- Seats too narrow
- Seat belts not long enough
- Discomfort when going over speed humps.

The Best Value inspection of Bromley day care services found concerns amongst users and carers about transport arrangements which were ad hoc and inequitable between centres (SSI / Audit Commission 2001d).

The Best Value review of older people's services in Hounslow (LB Hounslow 2003) found that there were problems with accessing public transport and particular problems with accessibility for wheelchair users on public transport.

Issues for BME groups

A report of a national conference on Chinese older people (Chau, Yu et al 2002) suggested that free transport should be provided for older people. There was much discussion at this conference about the isolation of Chinese older people from society in general and that many were isolated from their own community. It was particularly important that they should be able to travel to places where they could access culturally appropriate services and support.

The lack of Dial a Ride services was raised at a seminar in London on BME perspectives on care (Patel 2001).

Social life

Most older people want to be in social networks and engage in social activities, though the extent that they are prepared, and able, to leave their own homes in order to achieve this varies; depending on their level of frailty, the environment in which they live, their cognitive abilities and their health. On the whole people seek less social activity outside their home as they get very old, but most still highly value social contact.

The value of social networks

One of the main findings of an Age Concern appreciative inquiry study on ageing in London (Walker, Radford 2000) was the importance of friends and a social network. A study of the aspirations and attitudes of older people (Hayden, Boaz et al 1999) found that older people wanted opportunities created for active participation, for example in employment, learning and volunteering. A study looking at the experiences of older people living in "extraCare" schemes (Bartholomeu 1999) found that location was important as residents like to feel that they were part of the wider community.

A study to determine outcome measures of home care from the perspective of older people (Henwood, Waddington 2002) found that social participation was second most important area to which they aspired. Another study looking at quality of life for frail older people (Patmore 2002) found the most dissatisfaction expressed was with problems in getting out of the house and social life. The more satisfied older people in this study appeared to have more social and practical support from families and neighbourhood.

Many older people are valued members of support networks. In an Audit Commission study older people pointed to the reality of their interdependence with others (Audit Commission 2004). A Joseph Rowntree Foundation (JRF) study on the experience of ageing (Godfrey,

Townsend et al 2004) found that interdependence; being part of a community where people care about and look out for each other, was central to a good life in old age. The essence of 'ageing well' was the ability to sustain inter-dependent lives and relationships that meet needs for intimacy, comfort, support, companionship and fun. As noted above, a study conducted in Edinburgh and Glasgow found that even when older people lived on upper floors of flats and tenements without lifts, they were, on the whole, prepared to suffer the inconvenience of negotiating stairs (or even not going out), rather than move away from neighbours (MacDonald 1999). A very recent report from JRF (JRF 2004) stated that older people had important roles in supporting families within communities. They are also the biggest providers of support to other older people.

Isolation

There are many references in the literature to isolation experienced by older people and the negative impact this has on their quality of life, health and morale.

The recent JRF report (JRF 2004) found that many older people remain isolated; living in one's own home with no support or contact can be as disempowering as the stereotype of a nursing home. A study in Scotland (Dewar, O'May et al 2001) found that participants in both care homes and the community felt isolated from their local community.

Whilst not being limited to BME communities it seems that isolation is a particular issue for BME older people. A report on age and race from Age Concern England and the Commission for Racial Equality (CRE) found that white older people are more likely to live alone than BME elders, but even in large families older people can feel isolated and there are significant numbers who do not live in family groups. This report also found that "invisible" groups, for example Armenians in West London, are particularly isolated and vulnerable (Age Concern 2000).

A JRF report of a study in a number of cities including London, found that Chinese older people are isolated from both the Chinese community and mainstream society. Common causes of detachment from mainstream society were language barriers, insufficient knowledge of social and public services, lack of awareness of social rights, low expectations of their lives in the UK, negative experience of retirement, poor mental and physical health and poor self-image. Factors leading to older people's detachment from the Chinese community included inadequate support from their family, low physical mobility and poor social networks (Wai Kam Yu 2000).

Participants at a listening event for older people from BME communities in Barnet, Enfield and Haringey spoke of intense isolation and fears of isolation as they grew older (Age Concern England, undated). They stressed that the importance of social activities to health and well being should never be underestimated by those providing funding to community groups and voluntary organisations. Similar feelings of isolation were expressed in Barking and Dagenham (Age Concern Barking and Dagenham 2000). A study of Greek and Turkish speaking older people with mental health support needs in Enfield (Yahioglu 2004) found isolation and living alone was a major issue for this group of people. One study found that family structures are changing; patterns of care need to take account of this (Patel 2001).

A study to ascertain what older people needed to overcome isolation and loneliness (Cattan 2002) found that services which aim to support older people are not often providing what older people themselves want. Loneliness and isolation need different approaches. Those

who are isolated usually require practical help or resources, whereas those who are lonely may need social support and extended social networks.

Older people said they wanted:

- To be involved in planning, developing and delivering activities that target social isolation and loneliness
- Practical, flexible and low-level assistance that helps them to remain independent, gain the confidence to identify their own solutions and supports them in retaining their own social networks
- Individually tailored solutions to meet their specific needs, with a variety of activities available within their local neighbourhood or within reasonable travelling distance
- Transport that takes their mobility needs into account
- Services that cater for specific groups such as carers, ethnic minorities, older men, those with hearing impairments and those who have been isolated for a long time.
- Support and encouragement to learn new skills as well as the opportunity to share their skills with other older people.

The social value of home care

As noted above a study looking at what determines the use of home care services by older people (Stoddart, Whitley et al 2002) found that having smaller social networks was a factor. Some older people value home care as much for the social interaction it provides as for the practical help.

A study designed to document what matters to older people about low level home care services found that many people valued the relationship with the frontline provider as much as they did help with the task (Clark, Dyer et al 1998). A study of quality of life among frail older people using home care services (Patmore 2002) found that some of the most isolated people did not seek day centres, but wanted more contact with particular home care staff whom they already liked and trusted and that individuals who visited frequently made a big difference to the morale of this group of people. This study also suggested that particular resources could redress mobility problems by, for instance, providing excursions out; though some older people were content never to leave home.

An ESRC study found that increased contact with others, rather than the specific form of help is likely to improve the self-esteem of housebound older people (Baldock, Hadlow 2002). The author went on to suggest that formal service providers should intervene early in almost any way that increases an older person's contact with others. There may be as much to gain by the promptness of the intervention as from detailed assessments and matching services to needs, particularly where the assessment process is likely to delay greater contact with others.

BEDS: HOSPITALS AND CARE HOMES

As stated above, much of the literature confirms that older people would generally (though not in all circumstances) prefer to stay in their own homes, with appropriate support. However, sometimes illness, disability, isolation or a combination of all of them may necessitate admission to hospital, or to a residential or nursing home. This may be for a short time or for an indefinite period. The literature is interesting and important since it is about the facilities that older people use when they may be at their most vulnerable.

Hospital admission and discharge

Information from older people, and studies that reflected their views, indicate that significant problems remain in planning and executing effective discharges from hospital. Little of the literature had been published recently enough for new initiatives to have taken effect, but the most recent CSCI study (CSCI 2004f) - see below - indicates some cause for optimism about improvements. There are no indications of any factors distinctive to London on this topic, though a number of recent London borough-based inspection reports mention discharge, and a brief summary of these are provided below.

Preventing admission to hospital

There is very little in the literature about preventing admission to hospital, although some of the material on home care and day care is clearly relevant to this. However, one study in Dagenham (Levenson 2001) found that some people feared that, given the extent of their disabilities, admission to hospital might signal the end of their time at home. People made some suggestions on how hospital admissions could be prevented; these were mostly small but significant things, such as regular visits to check if a person was managing well, and help with making a cup of tea. In addition, better advice on medication and more respite care were suggested as ways to reduce hospital admissions.

What older people want

The Health and Older People (HOPe) group, convened by Help the Aged state that discharge from hospital should be properly prepared. It should involve patient and family and nursing and personal care should be in place for older people when they return home from hospital. Last but not least, older people should never be sent from hospital to permanent places in residential or nursing homes without proper consideration of rehabilitation (HOPe Group 2000).

Discharge – older people's experiences

As mentioned above, in 2004 there was an important new study on leaving hospital from CSCI (CSCI 2004f). This looked at individuals' experiences of the effect of the Government's reimbursement policy implemented in January 2004. It examined seven areas including Lambeth and Waltham Forest.

Key findings of the study were:

- The amount of extra time that people spend in hospital because their council had not arranged care almost halved between October 2003 and January 2004
- In the best areas, people get the choice of a full spectrum of care services with good access to rehabilitation and intermediate care

- The best areas put people and their interests first, and systems and processes second.

But the study also found:

- Wide variations in what happens to people when they leave hospital, with the number of people going directly into care homes varying from only one in 25 in some areas to more than one in three in others
- In some parts of the country, half of older people leaving hospital have to go back in again within three months, while in other areas only one in 12 are readmitted within this time
- Concerns that some people are being admitted to care homes when they could have been supported in their own homes
- In the poorest performing areas people do not have any meaningful choice about their future care.

In Barking and Dagenham, Havering, Redbridge and Waltham Forest the local Age Concerns reported that there should be more thought about review planning, including moving patients and discharge arrangements. They said that older people should be included more equally in these discussions (Age Concern Barking and Dagenham, Havering, Redbridge and Waltham Forest 2004). BME older people in Waltham Forest felt that hospital discharges were badly managed (Age Concern Waltham Forest 2004b).

A CHC discharge survey in Barnet (Guest 1999) found that 27% of people reported having no discussion about discharge and discharge planning did not take place early enough in the hospital stay for 87% of patients. Other discharge-related problems included:

- Information often not given about nursing homes and voluntary organisation services and home nursing services
- High number of patients did not receive a letter for their GP or an appointment card for follow up
- A small minority had problems with transport home
- A small minority did not get a GP visit once home
- Some delays with pharmacy and getting medication to take home.

A study commissioned by the London Borough of Richmond upon Thames Health Overview and Scrutiny Committee about older people's experiences of hospital discharge (Age Concern Richmond Upon Thames 2004) found that:

- The overall provision of information on hospital discharge was poor
- The system of assigning a named nurse was not working
- The experience of involvement of relatives / carers /friends was generally good
- On the whole the leaving day went smoothly
- Patient experience on discharge was worse for people who were in hospital for relatively longer periods or who were discharged to a care home
- On the whole, care packages were delivered promptly and there was a high level of client satisfaction with quality of care at home
- The system of temporary care home placements seemed to be working
- There were serious grounds for concern about the way that older people are sometimes communicated with in hospital which can affect their experience around discharge

- The real and perceived pressure for speedy discharge was being passed from hospital staff to patients and relatives.

A CHC visit in Bexley found one patient had not received any information on discharge procedures and was being discharged that day (Bexley CHC 1999) and Croydon CHC found that in their area the Elderly Hospital at Home Team was effective in enabling early discharge (Croydon CHC 2002a).

User influence and control over the discharge process

Another study in an unspecified location (Reed, Pearson et al 2002) found that:

- Having knowledge of the system was important to people in achieving a successful discharge
- Communication between all agencies and individuals is important
- Carers and older people need to feel in charge of process
- Older people felt reassured when services checked up on them to see how the discharge had gone – this was identified as an important component of a good discharge.

The issue of user influence and control was also explored in another study of older people's discharge from hospital (Roberts 2001). Some people felt that it was their role to initiate gaining access to services and had tried to do so, whereas others felt it was in the remit of professionals. Older people generally assumed an active role in getting social care and support, but lacked information about where to go for it and what was available. One study noted a particular need for communication when older people are being discharged from hospital. People wanted to know more about their condition and what to expect after being discharged home (Ashton, Annett et al 2001). This study also found that older people did not like conflicting information.

Finally, Age Concern made a specific point about problems when older people in a hospital outside their resident borough are discharged home as they may have problems getting community health services and social services on discharge (Age Concern 1998).

London inspection reports

The CSCI inspection reports in Havering (CSCI 2004d) and Hounslow (CSCI 2004e) note that hospital discharge is good or improving. A number of joint reviews comment on hospital discharge:

- Good use has been made of monies provided to enable better arrangements for discharges from hospital – Haringey (SSI / Audit Commission 1999)
- Good safe and rapid discharge from hospital facilitated – Croydon (SSI / Audit Commission 2000b)
- Increasing numbers of older people are supported intensively at home and hospital discharge arrangements are effective – Greenwich (SSI / Audit Commission 2002b)

In both Havering (CSCI 2004d) and Hillingdon (2004c) it was reported that the focus on reducing delays in hospital discharge may have had an adverse affect on the availability of services for people in their own homes which could prevent admission in the first place.

Intermediate care

The literature does not abound with direct references to intermediate care. This is possibly because material that reflects older people's views tends not to major on service configuration, or new ways of organising (or describing) services, but rather it commonly describes their needs and their experiences, including perceived gaps in service provision or quality. Some of the comments made by older people elsewhere are relevant to intermediate care, but older people are probably more likely to frame their comments by reference to hospital admission and discharge. Although intermediate care is not necessarily a service with "beds", it is considered here as so much of it is still delivered in a hospital or residential care environment.

A study conducted to raise awareness of, and get feedback on, the work of the intermediate care services and the home care services provided by Tower Hamlets PCT and social services (Begum, Miah 2004b) actually elicited few comments on intermediate care, with the majority of comments being on home care. However, this study found that access to services was a very big issue especially where there is a language barrier; some groups (for example Somali men) knew of no service where they could get interpretation and advocacy support. Also, levels of knowledge about services available and older people's right to them varied from group to group. However, there are some indications in the literature of what older people think about intermediate care services, and these are described below.

Older people's views on intermediate care services

One of the main studies of this topic was conducted in the west of Scotland (Petch 2003). It found that:

- Monitoring and supervision of home care staff are essential to promote confidence amongst older people which would make them happy to return home, secure that services would be provided appropriately. Older people returning home are seen as potentially vulnerable
- There were concerns about the NHS emptying beds, regardless of whether or not services are available which makes older people very cynical about discharge planning
- The availability of convalescence/halfway house support was considered important for a number of reasons, including not putting too much pressure on carers when patients are desperate to get home but not really ready, and to provide a social environment for recovery
- Community teams should be well enough resourced for the task at hand
- Separate convalescence should be provided for those with challenging behaviour
- Planning should be brought down to the local level as each area is different – this allows local accountability if the service is not being provided appropriately
- Regulation of domiciliary care should ensure that staff providing these services are well monitored and supervised, although it was recognised that personalities play a big part in how well services are provided
- Recognition that the roles of the staff involved in domiciliary care had changed over the years and that the reduction in tasks performed – the "it's not my job" culture – had affected older people's confidence in home care services.

Elsewhere, there are only passing mentions of intermediate care. In Havering, hospital discharge was seen as quite good, using intermediate care (CSCI 2004d), though, as mentioned above this may have been at the expense of the home care services. In Newham,

it was observed that intermediate care needs to link more with housing (Newham HIMP 2003).

Waltham Forest CHC visited an intermediate care unit and found largely pleasant facilities and a system whereby discharged clients were followed up by the unit with two home visits in the first week to ensure they are coping well, and, if necessary, the Hospital at Home Team were involved for therapy and support (Waltham Forest CHC 2003).

Long-term residential and nursing care

The literature on residential and nursing care looks at how older people view the prospect of such care and how well they are able to make an informed choice about it. It also looks at some of the factors that make a quality residential service from the point of view of older people. Unsurprisingly, there was a strong preference for remaining in one's own home for as long as possible. "Home" has a powerful emotional and psychological significance especially for people who had lived in their own home for many years. The option of residential or nursing home care was usually viewed very much as a last resort and participants in one study were critical of situations where people were "pushed into nursing homes too soon" (Henwood, Waddington 1998b). In one study, older people talked about residential care as something to be avoided for as long as possible if not forever (Clark, Dyer et al 1998).

Residential care sometimes the only option

Although the desire to stay at home is probably equally strong whatever part of the country older people live in, a major Audit Commission report stated that people living in some areas can choose from a range of specialist services in the community for example home care, respite and extended day care, but in others only residential and limited day care is available (Audit Commission 2000). However, in some areas there was also evidence that the number of people supported at home had increased and the number entering residential and nursing homes had decreased (CSCI 2004b).

Older people could not always easily achieve the care option that they wanted. Focus groups in unspecified locations showed that older people thought that some were pushed into nursing homes because of the inadequate development of alternative services that could help people stay in their own homes. Also, there were perverse financial incentives which made it cheaper for local authorities to admit people to residential care than put in place support packages to keep them at home (Henwood, Waddington 1998b).

Lack of advice about options and costs

In Camden, older people cited a mixture of reasons for going into a residential home including health, mobility, social and emotional problems. Several had gone into the home straight from hospital and had found it difficult to be involved in the decision. At least 33% said that it was their decision and a small number said they had had no choice. 25% said that they had had no information to help them make the decision (Dalley, Hadley 2000).

Service users in Croydon indicated that more information should be given to residents regarding options and what to expect when entering residential care. In the majority of cases, it was a relative who had first requested the service rather than the service user themselves.

This is an important point to note as for most other services provided by social services it is the person's GP or other professional who identifies the need (LB Croydon 1999).

A Newham Best Value survey showed that a number of residents stated that they wished they had been given more information about the placement process and how issues like finance worked (Darcy 2001).

Older people who owned their own homes particularly suffered from a lack of advice about their options for residential care and its costs. Interviews in five areas of England with privately paying residents and relatives showed that it was common for both groups not to have understood the complexities of the current means test before admission. A minority of relatives had talked to a local authority social worker. Some had gone to a care home provider for advice, some to banks, financial advisers and friends (Wright 2000).

Choosing suitable places

Choosing a residential care home was often difficult for people who needed to weigh up different factors that were important to them. One study noted the tension between wanting to choose a Methodist Home and wanting a home geographically close to home (Kellaher 2000). However, for some, choice was undermined by a lack of availability of care home places, particularly if one had special needs or was from a particular ethnic group.
For example, one study, conducted mainly in London, found a shortage of care identified for elderly mentally ill clients, including those with dementia and confusion and particular difficulties in finding residential or nursing home care for minority ethnic people in London especially Polish, Greek and Black Caribbean elders (Care Homes Information Network 1998). An Audit Commission study found that residential and nursing homes are supported by specialist mental health professionals in only four of twelve areas (Audit Commission 2000).

For some, choice of home was undermined by perverse financial considerations. A study of six local authorities, including one in London, found that choice of residential or nursing home was particularly curtailed where limits on the fees that local authorities will pay meant that some homes would not take local authority clients, or would ration the number of places available to them. This also had a knock-on effect on older people who were funding themselves and who mostly pay more than local authority supported clients and thus are subsiding statutory provision (Help the Aged 2002).

In Newham, many older people felt they were given a fairly wide range of choice of their home, but a significant minority (around 30%) did not. This may have been due to several reasons, some of which were not in the council's control, for example the wishes of residents or their relatives (Darcy 2001).

When residential homes close

Having made a choice of home, further choices may need to be made if a home is to be closed. One study (Williams, Netten et al 2003) looks at the process of closing residential homes – a process that can hit particularly hard as residents will have already made a choice and will have settled down in a particular environment. The report of this study found the closure process varied; notice of closure ranged from over a year to three weeks and relatives found out about closure from a variety of means including letter, rumour or articles in the press. 25% of relatives said the responsibility for notifying residents of closure was left to them.

Residents and relatives worried about having to accept a temporary placement and so move again. These moves were seen as a forced and negative choice associated with further distress and potential deterioration in residents' health. Residents and relatives valued openness and clear communication from providers and council staff about what was happening during closure period. A lack of vacancy lists was identified as unhelpful as were inadequacies in some of the councils' lists of homes in the area. Receiving help and support from the provider and council staff was valued, as was cooperation between provider and councils. For some, contact with council staff was disappointing and the lack of assistance was a serious difficulty.

Some 40% of those interviewed in this study said that a care manager had reassessed the resident's needs. The majority visited new homes to help their decision but none of the residents appeared to have visited a home after a decision had been made as a way of preparing for the move.

A main concern of relatives was the maintenance of standards during the closure period. At three of the eight homes standards were described as unpleasant, unacceptable and upsetting. Relatives feared for the safety and health of the residents. This was due to falling staff levels, the use of agency staff, lack of management control and maintenance of the environment. The actual move was a source of considerable distress and concern for some relatives. The relatives tried different strategies for minimising distress, but did not know what the best course of action was and received little guidance in handling the process.

Relatives and residents made recommendations for best practice:

- There should be at least two months notice given
- Notices should be flexible – not specifying a day
- Notification to relatives should include some opportunity to meet with the owner
- Providers should notify social services departments before relatives are told so that they can be ready to respond and help relatives
- Providers should be open about the possibility of a closure
- Notification should include the reasons for closure and information about where there are vacancies and what relatives should do now, and the timescale
- Information should be provided (by providers and social services departments) – about vacancies, changes to timescale, quality and facilities at other homes
- Social services should be proactive in contacting and supporting relatives
- There is a need for impartial and expert advice
- Assessments of needs should be carried out and conducted promptly
- There should be overall planning so that residents could be co-relocated where possible and desired
- Residents should be accompanied to visit new homes and have their views on them respected
- Standards of care to be maintained during closure period
- Signs of packing should be kept a minimum whilst residents were still in the home (especially in communal areas)
- Visits by developers and builders were considered to be insensitive
- Practical help should be offered to relatives and resident for the actual move
- Residents should be introduced to a key worker on day of arrival and someone should be dedicated to settling them in

- Residents should be given opportunity to spend time with other residents and staff from the closing home if they wish
- There should be recognition that people coming from other residential homes may have different needs than those coming from home or hospital.

Quality in residential care

Most of the literature on residential and nursing home care is about the quality of such care, and many similarities occur across the studies, regardless of where they took place. Characteristics of residential services that were associated with better outcomes of quality of life included greater "homeliness", homes that were part of the community, a focus on individuals and higher levels of attention shown by staff to residents (Henwood, Waddington 2002).

Work conducted with frail older people in residential care homes (Tester, Hubbard et al 2003) found four key issues affecting their quality of life. These were:

- Individual residents' activities
- Their relationships and interactions with other residents, staff and visitors
- Maintaining the individual's identity and autonomy
- The physical environment of the home.

Gender, social class and ethnicity also affected perceptions and experiences.

A study conducted in North West England, West Midlands and Wales (Abbott, Fisk et al 2000) noted:

- A significant minority of residents expressed concerns about the routines of life such as meals and social contact
- Staff expectations of social participation were often unrealistic – for many residents social contact was more a matter of adjustment than friendship
- Residents did not participate in deciding how the residential settings where they lived should be organised and managed, except for helping with simple domestic tasks
- Very few older people felt able to make suggestions or complaints
- Inappropriate communication with residents for example relying on notice board when some residents could not read it.

In Southampton, a study noted the following observations about quality from the perspective of the residents:

- A high level of importance was placed on social and recreational aspects of residential life
- Almost all residents expressed a wish to go out (sometimes linked with social contact, but more often just to be outdoors)
- They wanted choice in relation to mealtimes, bedtimes and privacy
- Good relationships with care staff are important (especially in response to illness or a request for help)
- Satisfaction was expressed with medical care
- Satisfaction expressed with standards of hygiene
- Satisfaction expressed with safety and security (Challiner 2000).

The mixture of concerns about the physical environment and social factors also emerged in another report (Henwood, Waddington 1998b) which noted:

- The physical quality of many residential homes was seen by participants as a vast improvement on earlier years, but people were not sure that this meant that the quality of care was satisfactory
- People were critical of the lack of adequate stimulation and lack of activities in homes.

A study of the views of people in Methodist Homes, mainly in the south of England, was valuable for some of the detailed observations about quality from an older people's point of view (Kellaher 2000). It found that residents identified mealtimes as particularly difficult and where the difference between domestic and residential living surfaced most clearly. Some residents commented on the strangeness of eating food they had not prepared. The quality of food and choice of food were sometimes issues, and it could be small things that mattered to older people, such as accommodating preferences for a particular type of tea. Some older people expressed concern about waiting times for staff attention and staff not having time to talk - residents wanted more socialising with staff whilst they went about their tasks.

Some were embarrassed by the need for personal care from care staff; age was sometimes mentioned as a factor in this, as was gender sometimes. Residents appreciated having their own individual toilets. Some residents preferred the Methodist Home because it dealt with incontinence well, with no smells evident in any of the homes.

A report on older people's priorities for health and social care (HOPe Group 2000) stated that residential care must be required to provide a decent quality of life, with respect for individual choice. Residents and their relatives and friends should be encouraged to be involved in developing and monitoring quality standards in all homes. On a more specific point, the report also discussed preparation for death and called for respect and understanding for those who are dying to be integral to all health and care settings.

Moving on to reports of London services, a Newham Best Value survey of elders in nursing and residential homes (Darcy 2001) found that:

- The majority of comments about staff were positive, but some residents felt that staff attitudes could be improved and there was a problem of understaffing.
- The ways in which residents could put forward suggestions or comments varied between the homes
- There were persistent complaints about catering and food, either in terms of quality or quantity
- Some racist comments were reported by residents, but it was not clear whether such comments were made by staff or other elders.

In the previous year another Newham report had looked at areas of importance to older people in residential and nursing homes (Cooney 2000b). Older people mentioned:

- Having something to do
- Having enough staff
- Having friendly and experienced staff
- Activities were not always what people wanted, or did not seem appropriate
- Living with others with whom they could communicate and whom they liked.

Whether the resident had things in common with the others already living there was important for how older people felt about a home. The majority of comments about staff

were positive, but some felt staff attitudes could be improved. Residents commented that staff were unable to spend enough time with them because they were so busy. The residents were not familiar with the key worker system, although almost 78% of managers said they had a key worker system in operation.

Residents' suggestions for improvements reflected these concerns, for example:

- More staff
- More activities
- Better food
- More medical input
- More time from staff
- More outings
- More visitors from the community
- More recognition of the need to place residents in a home with others of similar needs and abilities.

In Camden, expectations of residential care had largely been positive. Worries included leaving belongings behind, loss of privacy, family problems and deteriorating health. The importance of having privacy was stressed and people very much appreciated having single rooms, though one person who shared was happy (Dalley, Hadley 2000). This report also said that some older people liked to have some meals on their own in their room, but this was generally discouraged by staff. The most important things for older people about their residential home (in order of citation) were:

- The company of other residents
- Helpful, caring staff
- Good food
- Good care and no pain
- Happiness
- Security and safety
- Being looked after
- Quality of surroundings and cleanliness.

Two thirds said that their home provided these and one third said it met expectations. A small number were not happy with the home. Residents with lower levels of confusion did not like mixing with residents who had higher levels of confusion.

Other issues that were raised were access to telephone, which was often restricted, and access to GPs, which was an issue for a minority of residents.

Positive views generally outweighed negative views and in answer to what was good about their residential home older people responded:

- Companionship and friendship
- Comfort, food, quality of care
- Quality of staff
- Privacy
- Activities organised
- Comfortable surroundings
- Greenery
- Location of home.

Specifically, they did not like:

- Poor food
- Other residents being difficult
- Having to wait to go to the toilet
- Imposed bedtimes
- Loss of past contacts.

Observations about quality from CHC visits

A number of snapshots of quality come from visits made by Community Health Councils (CHCs). This, incidentally, raises interesting issues about the possibility of a deficit in information in the future, since the reports from these CHC visits are unlike reports available from other sources.

A Waltham Forest CHC visit to a unit for mentally infirm older people (Waltham Forest CHC 2001) noted:

- Inadequate foot care service (reduced to six-monthly from three-monthly)
- Complaints about quality of cook-chill food (but improved menus were being planned)
- Need for more rooms for showers and bathing
- There were a lot of activities provided - occupational therapist was there for half the week, but a programme including cooking, crafts and reminiscence ran throughout the week
- The CHC wanted to see the introduction of a special sensory room and more money and resources for the small activities budget.

Barnet CHC undertook a series of visits to residential and nursing homes where local residents had their care funded (Barnet CHC 2001b). They found some recurrent points of concern:

- Problems about funding of percutaneous gastrostomy (PEG) giving sets
- Limited access to wheelchairs
- Lack of physiotherapy
- Uneven provision of activities
- Access to chiropody varied from weekly to three-monthly, and fees for it varied
- Access to dentistry was usually reasonable, but long waits in two places.

Barnet CHC also produced a summary of nursing home visit reports, discussion with providers and residents brought together in a symposium (Barnet CHC 2001a). This found that residents valued:

- Being listened to by staff
- Being known as "people" and having personal problems attended to
- Effective complaints management
- Good staff recruitment; checking of references etc.
- Focus on them as individuals; not all activities in groups.

Relatives valued homes that welcome their contribution, for example helping with meals.

In some of the Barnet homes, residents were concerned about the same kinds of issues that have been noted elsewhere, including concerns about the fabric of buildings and staff being

too busy to talk. They were also concerned about inexperienced staff due to high turnover and there were some complaints about the food – either not enough to eat, or the food being cold or the same as the previous day.

A CHC visit to a nursing home in Croydon (Croydon CHC 2002b) found that:

- CHC visitors were impressed with the appearance of the home and its facilities
- Food was excellent and plentiful
- There was a shortage of Occupational Therapists.

CHC visits were often valuable for the small, but important, details that they observed. A Newham CHC visit to a nursing home saw that the wider use of adapted cutlery and feeding aids was needed, as well as food warmers for residents who were slow eaters (Newham CHC 1998). This kind of material rarely appears elsewhere in the literature.

CHCs were also willing to record good practice. Newham CHC commended a nursing home where there were personalised rooms, links with local schools and where bereavement counselling was considered a priority (Newham CHC 1998). However, they were also concerned that cultural were needs not always met.

Positive aspects of residential care

In spite of the many shortcomings of residential care and the loss of independence that many people feared, the literature has numerous references to positive aspects of residential care. Older people often had a negative perception of residential home whilst still living at home, but when in residential home many, but not all, accept the support and find a way of expressing independence within it (Fisk, Abbot 1998).

It was not inevitable that those living in residential care were less able to do what they wanted than others. A study in Belfast found that older people living in institutions perceived themselves to have greater autonomy in their decisions than older people receiving domiciliary care (Boyle 2004).

An analysis of UK literature found that older people who have made the move to residential care can often identify advantages of their new homes (after a period of adjustment) including the safe environment, the care they receive and the company of others. It is evident that moving in itself, and not just the prospect of residential care and loss of independence, was unattractive. Residents in care homes express a desire not to have to move again (Boaz, Hayden et al 1999).

A study conducted in some Methodist Homes found that the majority thought they had made the right decision to go into residential care. Many were glad they no longer had to do chores such as shopping. People also mentioned things that they liked, such as the option of being able to have breakfast on a tray in their own room. It was also important to be able to go out. Consultation with the staff and involvement in decisions about the home (a feature of Methodist Homes) was appreciated (Kellaher 2000).

Studies of satisfaction with residential care also tend to show broad satisfaction with residential care homes. In Croydon 90% of the surveyed residents who live in the council-run Part III homes, thought that their opinions were listened to and more than 90% thought they received the correct service for their needs. Across the private and voluntary sector and the

council-run homes residents on the whole thought that they were receiving the correct standard of service (LB Croydon 1999).

In Newham, a survey showed that new residents showed a higher than average level of satisfaction, with over 95% considering their home good or fair (Darcy 2001).

BME older people's needs in residential care

The need for culturally sensitive care services of all kinds is a recurrent theme in what older people say about their services. A conference of Chinese older people specifically called for Chinese nursing homes with Chinese workers (Chau, Yu et al 2002). The conference report also includes a presentation from Paul Chow on his experience of meeting older Chinese people's needs in Glasgow in the Wing Hong Elderly Group, managed by volunteer Chinese older people for the Chinese older people. The centre runs a range of activities and support services, including developing a Chinese wing in a mainstream residential home. There are 8 Chinese residents and the home employs bilingual staff to look after them. The Chinese kitchen delivers dietary requirements.

This would accord with a recommendation made by Chinese older people in a multi-site study that included London. Chinese older people called for the right to choose their own diets in residential homes (Wai Kam Yu 2000).

A study of the views and experiences of dementia among South Asian people and their carers identified strong views about residential care, which was seen as insensitive to the needs of South Asian people (Bowes, Wilkinson 2003).

Gay and lesbian concerns about residential care.

There is very little material about the needs and experiences of gay and lesbian older people in the recent UK literature. However, one conference report indicates that many lesbians and gay men are worried about going into care as they have a fear of homophobic staff and residents (Sale 2002).

SPECIAL NEEDS

There is some reference in the literature to older people with particular needs. These include sensory and other disabilities, mental health problems and dementia. Most of this literature is concerned with older people who have dementia and their carers.

Older people with dementia

Seeking the views of older people with dementia is difficult, though the difficulties are not insuperable. A recent review of literature in Scotland found that there was an international network of researchers concerned to hear the voices of people with dementia and that with appropriate methods and support older people with dementia can contribute to research and have the potential to express their views (MacDonald 2004). Many of the studies reported here contain a mixture of views of older people with dementia and those of their carers.

A major review of mental health services for older people in England and Wales (Audit Commission 2000), which included a survey of carers of older people with dementia, suggested that the number of older people with mental health problems is growing rapidly. It also stated that:

- The older old will need most help from services
- Getting help and advice quickly is vital for family carers
- Many GPs are unable to provide appropriate advice
- Commissioners of health and social care services worked together in only four out of twelve areas. But innovation and joint work has led to examples of flexible and responsive care for some users.

The report of this review went on to say that specialist help for users and carers is patchy and often uncoordinated:

- Expenditure on specialist services per person over 65 varies by 8:1
- People living in some areas can choose from a range of specialist services in the community for example home care, respite and extended day care, but in others only residential and limited day care is available
- Residential and nursing homes are supported by specialist mental health professionals in only four out of 12 areas
- Written information about the care of individuals was routinely shared in only three out of 12 areas.

An update of this review two years later (Audit Commission 2002a) found there were still wide variations in practice and provision of mental health services for older people across England. This report made the following recommendations:

- More support and training for GPs
- Better information (including good written information) for carers about local services
- Specialist services need strengthening in some areas
- More day and respite care needed
- Teamwork and strategy need further attention.

Experiences and needs of older people with dementia

A major study of older people with dementia, conducted in various sites including one in London (Moriarty, Webb 2000) found that the assessment process often caused anxiety amongst service users. This study also found that, although some older people with dementia liked day care, a minority found it an "ordeal". Short term care was valued by carers as time off from caring, but they were often concerned that it was not of benefit to people with dementia. As noted above the carers were critical of meals services and preferred home helps to prepare food and stay to ensure that they ate it. Home based care was valued by the carers as respite, but not favoured over day care for the retention of the person's social skills and interests. Residential care was valued for the safety aspects and was particularly acceptable if the older person with dementia was able to maintain their old lifestyle within residential care.

A recent small scale study of care at home for older people with dementia in various parts of London found routine was very important to carers and people with dementia (Redfern, Norman et al 2002). This study found it was essential that care services should aim to fit into the routines of the carers and older people with dementia and that where they did not they could be seen as more of a hindrance than help.

A study looking at outcomes of home care for older people with dementia (Wenger, Woods et al 2002) found that early interventions did not improve outcomes for people with dementia or their carers. In particular, early intervention did not delay admissions to residential care and nursing homes. The most valuable intervention was from a dementia care specialist, both in providing practical help and assisting the family in dealing with stresses and changes.

Various studies of older people with dementia focus on the needs and experiences of carers. A major study of older people with dementia at various sites, one in London, found that few carers were offered, or had, a separate assessment of their needs, though often their needs were incorporated in the service user assessment (Moriarty, Webb 2000). Also the information needs of carers were not always met. Carers wanted (and were often lacking) three types of information; firstly diagnosis and prognosis of illness, secondly what help was available, and how to access it, and thirdly sources of voluntary sector support and advice.

Carers who did not live with the person they cared for valued home care visits for the reassurance that someone was checking on the person with dementia and the social contact. Many carers gradually adjusted to ceasing to care when the person they cared for moved into a care home and most were pleased with the decision after a time. If the person they cared for was in residential care, many carers remained involved in decisions and review meetings even though they no longer directly cared for person with dementia. An interesting finding in this study was that carers did not always recognise the term "carer" applied to them (Moriarty, Webb 2000).

A study of the experiences of people caring for a relative with dementia found some positive aspects, but mainly focuses on the challenges (Pickard, Glendenning 2001). Night time wandering and night time incontinence were found to be some of the most challenging aspects, particularly as they disrupted the carers' sleep. This was often the deciding factor that led to a move to residential care. Personal care giving was also highly challenging, both practically and psychologically. Sometimes it was also distressing for the person with dementia. Respite care was unacceptable or unsatisfactory to many carers and all had reservations about it. Some had rejected it after trying it and there were many reports of falls and infections occurring during periods of respite care in nursing homes.

Another study found that the role of Community Psychiatric Nurses (CPNs), who are the key professional group supporting older people with dementia, was not often understood by carers. CPNs did not give practical help, nor did they always act in the role of key worker to organise the help carers needed to support them to care (Pickard, Glendenning 2001).

A number of studies explore the particular difficulties for BME people with dementia and their families. A study of South Asian and African Caribbean families caring for someone with dementia in various parts of England, including London, found:

- Accessing services is difficult and complex for people from minority ethnic groups
- Caring for someone with dementia and identifying oneself as from a minority ethnic group both lead to marginalisation and social exclusion
- Racism and discrimination play their part in people's experiences of accessing and using statutory services
- The terms "dementia" and "care" do not connect well with people's lived experiences. Professionals need to use the language of clients (Forbat 2003).

In this study interviewees felt that practitioners need to demonstrate more awareness of their understanding of how dementia affects not just individuals, but whole networks of family relationships.

A small study in North London of Caribbean-born people with dementia (Butterfield 2002) also found difficulty accessing services and consequent low use of state services. Most of the support this group received was provided by voluntary organisations and informal support networks including the church.

A survey to look at the needs of Greek and Turkish speaking older people with mental health problems in Enfield, North London (Yahioglu 2004) again found low access to, and uptake of, services. This study also found a lack of understanding of the term mental health by first generation Cypriots and a stigma regarding mental illness within both Greek and Turkish speaking communities. The report of this study makes a number of recommendations:

- Need to raise awareness regarding issues relating to mental health, depression and dementia within the BME communities of Enfield
- Need to tackle isolation and promote inclusion of elders with mental health support needs
- Need for a day centre for BME communities in Enfield
- Need to approach mental health support needs in Greek and Turkish communities in a holistic way
- Provide support to carers
- Cultural awareness training needed for support staff
- Linkage of community groups to Alzheimer's Society Enfield and Dementia day care Services Age Concern Enfield
- Need to employ staff from Turkish and Greek communities
- Ensure there is adequate referral to statutory services for those with mental health needs.

<u>Problems with level and quality of care for older people with dementia in London</u>
A review of the Care Homes Information Network (CHIN) found a shortage of care in London for elderly mentally ill older people, including those with dementia and confusion

(Care Homes Information Network 1998). A recent CSCI inspection report of Redbridge social services praised the local dementia services, but said that there were still gaps in availability of residential and nursing home beds for people with dementia. Consultation with older people in Barking and Dagenham identified a need for day services for people with dementia (Age Concern Barking and Dagenham 2000).

A report from the Alzheimer's Society in 2002 found that the free nursing care policy was not working well for people with dementia and that it had lead to a reduction in the quality of care in some instances rather than an improvement (Alzheimer's Society 2002).

Various CHC visit reports relate to residential care for older people with mental health problems. One found a strong smell of urine and problems with baths and access to hoists (Waltham Forest CHC 2000). A report of a visit to another facility was more positive and found that residents generally liked being there, though the fabric of the building was poor and there was only one activities coordinator for 50 people. There was also a reduction in respite care beds and some problems in non-emergency transport to the local acute hospital, because of limitations to the ambulance contract (Waltham Forest CHC 1999). A report from Wandsworth CHC commends the links between a local residential care facility and voluntary sector organisations such as the Alzheimer's Society and the Relatives Association. Also seen as positive were the open visiting hours (Wandsworth CHC 2001).

Older people with sensory and other disabilities

The report from the Help the Aged HOPe Group (HOPe Group 2000) raises issues about older people living with long-term conditions and disabilities. This recommends the promotion of self-management amongst older people. The report also states that older people with debilitating pain should be referred to pain clinics as a matter of course, with the implication that this is not always what happens in practice.

A study looking at the housing and support needs of older people with visual impairment in various cities including London (Thomas Pocklington Trust 2002) found:

- Little professional awareness of late onset visual impairment and its effects (emotional, anxiety, depression, profound loss) - often people not offered help
- Unmet needs for support and assessment and provision of equipment (particularly for reading) - need for regular review not met
- Older people wanted to stay in their home when losing sight as own home more familiar
- Loneliness and loss of contact with neighbourhood experienced due to problems negotiating outside world
- Poor knowledge of support groups, community services and specialist housing options
- People expressed a need for a source of reliable information.

A consultation workshop with older people in Newham (Newham HIMP 2003) found that links needed to be built with services dealing with sensory issues; hearing and sight, as older people with sensory problems found it took a long time to go through the different agencies and get help.

Older people with learning difficulties

One study, from the Joseph Rowntree Foundation, looked at services for older people with learning difficulties (Fitzgerald 1998). This study found:

- There was wide variation in the provision of services for older people with learning difficulties.
- There was confusion surrounding who is responsible for providing services for people with learning difficulties over 65 years old.
- In some areas there was no real impetus to resettle older people with learning difficulties from long-stay institutions.
- There were examples of good practice in the resettlement of older people but little means of sharing these with other providers.
- There was wide lack of respect for the future of older people with learning difficulties in terms of expectations and their potential for greater independence.
- There was a marked lack of opportunity for older people with learning difficulties to develop networks with others of similar ages or interests.
- Many older people with learning difficulties would have preferred being cared for by other older people, with similar interests to themselves.

ISSUES FOR BLACK AND MINORITY OLDER PEOPLE

Much of the literature reviewed for this study contained references to the needs or experiences of BME older people in relation to care services. In some studies, the views of BME older people were described as part of a wider study of an area or an issue where BME and other older people were considered in relation to a specific need or service. In a number of studies, the focus was particularly on BME older people, either with BME older people as the main subject of study, or in specific consultations and listening events involving BME older people.

Many of the important issues for BME older people are discussed elsewhere in this report. For example, the sections on information, access, home care, day care, residential care and social life all contain important material. However, this section brings together the main points that appear to be relevant to BME older people and their carers so that the wider picture can be seen.

Similarities and differences in areas of concern

Although many of the issues in this report highlight where BME older people have particular experiences or needs, it is also noteworthy that many of the concerns of BME older people are essentially similar to the views of older people from majority communities. For example, a study in London, Edinburgh and Leeds (Patel 2001) found that, in addition to specific points about language and communication and information, BME older people were also concerned about broad issues such as too many agencies dealing with one problem and the need for better care at home. However, this study also makes the valuable point that many commonplace problems, such as a lack of information, are made worse due to language difficulties, poverty and other factors that are more frequently found in BME communities. It is also suggested that poor systems (for example appointments systems) would have greater impact on BME older people (Levenson 1999).

A comparative study conducted in Scotland of needs and provision of care services in relation to the older Asian population compared with the older Scottish population generally found that the needs were very similar, though there was a marked difference in use of services with 27% of the majority group using services from home helps or carers compared with only 7% of the Asian group (Bowes, MacDonald 2000).

Some studies point out that the experience of sub-optimal care services is harder for BME people because of lower income (Patel 2001) or poorer health or housing (Age Concern 2000) than that experienced by majority communities.

Experience of racism/discrimination

BME older people continue to experience discrimination and racism and this affects their experience of care services. A study in Wales referred to institutional racism and suggested that stress results from the daily experience of being a minority (PRIAE 2000). One report indicates that older people at a London seminar experienced racial discrimination in care and assessments (Patel 2001), while another in Milton Keynes, Birmingham, London, Luton and Aylesbury found that racism and discrimination played their part in people's experiences of accessing and using statutory services (Forbat 2003). In Barnet, Enfield and Haringey participants had experienced racism over many years, and still experienced discrimination in 2001 when receiving services (Age Concern England, undated).

Chinese older people in London felt they experienced discrimination such as waiting longer for appointments in health settings. They reported sometimes meeting hostile responses when trying to make themselves understood (Help the Aged 2001b).

In spite of these findings, it has been suggested in a study of eight local authority areas which had significant BME groups (and a few of them with the highest number of Black elders in the country, including Hackney and Hounslow) that policies and procedures for the protection of older people were mostly generic and did not specifically address areas like racial abuse and harassment (SSI 1998).

Services generally perceived to be poor

The overwhelming impression is that care services for BME older people continue to be poor, although that is not to say that they are uniformly good for any ethnic group. In Havering an inspection criticised a longstanding lack of attention to the needs of BME communities. Services were purchased from other boroughs instead of local services being developed and older people had to travel long distances for these (CSCI 2004d). In Harrow a survey of home care users noted that a low number of service users were asked to identify specific cultural needs (LB Harrow 2004).

In north London, African Caribbean carers of people with dementia spoke well of individuals who had helped them, but generally they felt let down or disappointed by state services and did not receive much help from social services at home (Butterfield 2002). Newham CHC found that cultural needs were not always met in a nursing home (Newham CHC 1998) while seminars in London reported that social services need to understand that BME communities are heterogeneous (Patel 2001).

There is some evidence that BME older people are less satisfied with the care services they receive than white older people (Department of Health 2003, Bowes, MacDonald 2000). This is discussed in the section on home care.

Evidence of good practice

There was also some evidence of good practice. A Best Value review of Islington's day services found the needs of some older people from BME groups were being met. There was evidence of specific arrangements being made, such as culturally appropriate meals and service users able to communicate with staff in their own language (SSI / Audit Commission 2002d). In Hounslow there were some highly regarded culturally specific services, some using direct payments (CSCI 2004e). A Redbridge inspection noted that the range of resources for BME users was increasing and supported by the independent and voluntary sectors (CSCI 2004b).

Sometimes the picture was a mixture of good and not so good. An inspection of community care services for BME older people found that overall there was a genuine attempt being made to ensure that the service to ethnic minority older people was relevant and accessible. There were some good examples of practice and service delivery. However, services offered limited choice to black older people and the ethnocentric nature of service provision meant that many had difficulty in having their needs met (SSI 1998).

Language and communication

A very large number of reports refer to language and communication issues. For BME service users and their carers the meaning of "communication" focused on whether care workers could speak the older person's own language (Francis, Netten 2004).

In Hillingdon a need was noted for a listening receptive approach from staff with good interpretation services where needed. Only five languages were available out of 55 known to be spoken in the borough, and only in a voluntary capacity (LB Hillingdon 2001). A report on BME older people's perspectives on long term care noted the need for better access to interpreters, plus training for interpreters to act as advocates (Patel 2001). It also noted "inter-ethnic issues"; for example a Punjabi speaking support worker could not understand a Punjabi speaking person from "back home".

In Waltham Forest, older people said that language difficulties prevented BME older people from accessing services (Age Concern Waltham Forest 2004c). Language and communication issues were also noted in Barnet, Enfield and Haringey (Age Concern England (undated), Tower Hamlets, (Begum, Miah 2004a) Barking and Dagenham, (Age Concern Barking and Dagenham 2000), Manchester (Raynes, Temple et al 2001b) as well as in London generally - for Chinese people - (Help the Aged 2001b).

Calls for better interpretation and translation services are common, but written material was not always seen as a panacea even if it was translated into appropriate languages. A report of inspection of community care services for black and ethnic minority older people found that leaflets translated into community languages were the most common means of making people aware of services, but without an effective communication strategy they did not reach their target audiences. Many black older people lacked any knowledge of the available services. Word of mouth was the most effective means of communication (SSI 1998).

Language issues do not only pertain to individuals using services. Consultation is also important and a recent workshop on strategy in Waltham Forest found that workshops in Asian languages, when held, are very successful (Age Concern Waltham Forest 2004c). In Barnet, Enfield and Haringey, BME older people would welcome opportunity to be involved in planning and decision making processes, if accessible and in their own languages (Age Concern England (undated).

Do BME older people want separate services?

A meeting of BME older people in Waltham Forest said that mixed services were wanted, but they must accommodate different needs (Age Concern Waltham Forest 2004b). There are a few indications in the literature of other older people wanting separate services, but it is difficult to assess whether this is an outright preference, or a result of mainstream services being currently unable to accommodate diversity. In Wandsworth specialist provider projects for BME groups were much appreciated and concerns were expressed about access difficulties and about the need to understand cultural factors in order to better provide appropriate services (Wandsworth Borough Council 2000).

One study reported a preference for culturally familiar and appropriate care centres and said that specific BME services are good, but they are few and far between and cannot meet all needs. As mentioned above, there was concern about financial threats facing BME specific day centres, as the participants did not feel comfortable at mainstream centres (Patel 2001). Chinese people also favoured some separate facilities. They called for government funding to

enable Chinese organisations to provide services for Chinese people and for provide resources to enable Chinese workers to attain qualifications to serve Chinese people. They suggested that cross-regional services should be provided so that, for example, Chinese people could choose to see GPs and use services outside their own districts (Chau, Yu et al 2002).

Black and minority ethnic carers

There is some indication of the persistence of stereotypical attitudes about BME families and their willingness, availability and capacity to care for older family members. The SSI report of 1998 found that some staff still take the view that BME communities "look after their own" (SSI 1998). Similarly, a seminar in London reported that social services departments seemed sometimes to assume that daughters would help, and there was sometimes no consideration of family resources. It was suggested that myths about family support create barriers to access to care and so providers need to update their knowledge of family structures (Patel 2001).

A consultation exercise in Tower Hamlets (Begum, Miah 2004b) found that carers welcomed the home care service and felt that social services should not assume it is the family's duty to take on the caring role. This report also found that assessment of carers' needs should be done in confidence as they may be reluctant to ask for support because of family pressure or stigma.

The small study of South Asian carers of people with dementia in Scotland found that carers wanted someone to come and sit and talk to the person with dementia to give them a break. This study (Bowes, Wilkinson 2003) also found that carers wanted help rather than advice.

As noted above, a report of various studies of Chinese older people (Wai Kam Yu 2000) found that the ability of middle-aged Chinese people to care for older dependents was often exaggerated. In common with older people they face difficulties, such as language barriers, in using formal caring services. They have a lack of knowledge of social services and difficulties in expressing health concepts from their own cultural perspective. They also have to deal with their own problems, such as economic pressures and occupational hazards.

The nature of the literature on BME older people

It may be positive that so much academic and other interest has been shown in BME older people. This is in marked contrast to some other groups of older people affected by inappropriate services and discrimination, for example gay and lesbian older people, to whom only one reference was found. However, much of the material from BME older people is depressingly familiar and repetitive, with little apparent progress as services develop; numerous studies point to unsuitable services for BME older people, with the same issues about access, information, communication and discrimination coming up time after time. This would seem to indicate that issues about care services and BME older people remain research-rich but action-poor, and it is necessary to ask why so many familiar problems persist in spite of the wealth of knowledge and suggestions for good practice to ameliorate the situation.

One author (Blakemore 2000) contends that the development of health and social care for South Asian and African Caribbean BME communities in Britain is often perceived as problematic. While this view is justified for some groups or sections of groups, due to demographic factors and social and economic disadvantage which result in lack of resources

to provide care, deficits in the planning and delivery of care to those groups and to racism and institutional discrimination; it may not be so for all. Blakemore goes on to argue that the problems of racism in the planning and delivery of health and social care services are serious and lead to limited access to and under-use of social services by some. However, he suggests that some minority ethnic communities are in a much better position than others to meet the care needs of older people. He states that relatively little attention has been given to BME older people themselves, rather than as objects of need or victims of racism and he asks whether the issues of care for BME older people have been "over-problematized". He concludes:

> *The position of minority ethnic communities has often been portrayed as one of common disadvantage compared with the position facing the white majority. In this way, existing research has tended to racialize the debate about minority needs, focussing on problems in community care as if they affect all black people equally. In fact, some minority ethnic communities are in a much better position than others to lessen the impact of "race" discrimination, inadequate care services and social disadvantage. All the signs point to increasing inequalities in community care among Britain's minority black and south Asian communities, while the black/white divide becomes less distinct than it was.*

While the other literature surveyed does not necessarily support these conclusions, it is, nevertheless worth asking why so much of the literature continues to supply repeated examples of inequalities of provision and culturally insensitive services, with so little evidence of radical change to address these serious issues.

CONCLUSION

For older people there is more to care services than providing personal care and assistance. Older people expect to be treated as individuals, having their particular needs met and their preferences respected in order to support their autonomy. The importance of social interaction and mental stimulation is paramount for many older people and they look to care services to facilitate this. Access to good quality day care is important in this respect, but many older people also value the social aspects of home care and would like to see this developed.

Older people wish to be independent and, for many, staying in their own homes is the most important factor in maintaining their independence. Frequently, however, older people find themselves isolated and dependent on care services for their social contact as well as their care. They tend to fear residential care, but sometimes find that it exceeds expectations if they do find themselves there; the company of others, and safety, being consistently reported as positive aspects of residential care.

Provision for older people should be primarily focused on promoting an approach to integrated services that enable people to receive the physical support and care they need whilst also promoting opportunities for social integration with other people. This should be a priority for those designing care services, housing and support with, and for, older people.

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Appendix one

LIST OF SOURCES SEARCHED

Databases

INVOLVE database (Keywords: older people)

Caredata (Keywords: Older people & User views)

Ageinfo database – two searches
1) key words: Elderly OR older AND care AND (residential OR domiciliary OR homes) AND consumer choice
2) Text: User*/carer* AND attitude*/view*
Key words: services/domiciliary services/day services/meals services

IDEA database (searched for Best Value)

ASSIA database (searched for key words in abstracts: residential OR domiciliary OR community AND care AND service AND elderly OR older)

Journals

Health and Social Care in the Community Journal – Blackwells (hand search)

Quality in Ageing Journal (hand search)

Generations Review (Hand search)

Health and Care

Ageing and Society Journal (Hand search)

Managing Community care (Hand search)

Websites

Audit Commission website www.audit-commission.gov.uk

Joseph Rowntree Foundation website www.jrf.org.uk

Greater London Authority Website www.london.gov.uk

ESRC www.regard.ac.uk

SPRU – University of York Social Policy Research Unit Website www.york.ac.uk/spru

PRIAE - Policy Research Institute on Ageing and Ethnicity website www.priae.org

Other

King's Fund library catalogue [Key words: London AND elderly AND (day OR domiciliary OR residential]

Age Concern London Groups (phone call and email trawl)

Older Peoples' Forum Newsletters

Help the Aged - library / resource room

ESRC, including Growing Older Programme reports

London CHC papers (at London Metropolitan Archives)

Relatives and Residents Association (phone call)

SSI / Audit Commission joint review inspection reports www.joint-reviews.gov.uk

London Boroughs (email and telephone trawl)

Appendix two

LITERATURE REVIEW FORM

Number e.g. NJ1 or RL1:

Title of paper / report:

Authors:

Date of publication:

Published and funded by:

Aims or purpose of study:

Methods of study:

Population of study (including size of sample and how selected and exclusions):

Main findings:

Geographical site of study (e.g. London, Newham, UK, Liverpool):

How we found the study:

How to reference the study:

Appendix three

LIST OF ABBREVIATIONS AND TERMS

Best value inspection or study	Review of local council services – expected to include some consultation with users.
BME	Black and minority ethnic
CSCI	Commission for Social Services Inspection
CAB	Citizens Advice Bureau
Joint review	Review of local councils conducted jointly by Social Services Inspectorate and Audit Commission
Age Concern	Charity concerned with older people in the UK – has local branches
Help the Aged	Charity concerned with older people in the UK
NSF	National Service Framework – Government standards for a service or group of people who use a service – an NSF for older people was introduced in 2001
SSI	Social Services Inspectorate
Audit Commission	An independent public body responsible for ensuring that public money is spent economically, efficiently, and effectively in the areas of local government, housing, health, criminal justice and fire and rescue services
DH	Department of Health
DWP	Department of Work and Pensions
Informal care	Term sometimes used in the literature to refer to relatives and friends who provide care to older people
Carers	Used on its own refers to unpaid (informal) carers – usually family or friends
Care workers	Those who are paid to provide care in people's homes or residential care institutions

PEG	Percutaneous gastrostomy – intravenous feeding device
CPN	Community Psychiatric Nurse
Direct payments	Cash payments made in lieu of social service provisions to individuals who have been assessed as needing services. Users then use the money to arrange their own care.