Care and support for older people and carers in Bradford

Their perspectives, aspirations and experiences

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How the take-up of services is affected by perceptions of how accessible and acceptable care and support is in Bradford.

This report explores the views of older people and their carers from ten ethnic communities in relation to their needs and experiences of care and support. It addresses two central areas of government policy and practice: the accessibility and acceptability of services to older people and their carers, and the barriers and facilitators to the take-up of services.

Topics were explored by 21 focus groups (137 older people; 33 carers) and in-depth interviews with 38 older people and 15 carers. The report covers the following subjects:

- What older people and carers say they need in terms of care and support, including emotional support, information and translation services.

- Experiences and expectations of support from family, friends and neighbours.

- Experiences and expectations of support by health and social welfare services, including eligibility to entitlements, experiences of good practice and barriers to accessing services.

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Executive summary

This study set out to explore the views of older people and their carers from a range of ethnic communities within Bradford in relation to their needs and experiences of care and support. In particular, it aimed to address two central areas of government policy and practice: the accessibility and acceptability of services to older people and their carers, and the barriers and facilitators to the take-up of services, such as language, cultural appropriateness, awareness, affordability and perceptions of services.

Findings from existing research

There is strong evidence in the literature that the belief that minority ethnic groups are self-sufficient in terms of care of their older dependants ('they look after their own') is unfounded. A number of studies have reported a larger proportion of multigenerational households among South Asian groups such as Bangladeshis, Pakistanis and Indians, even though there is evidence that the proportion of such households among Indians has been decreasing. However, findings from empirical research have shown that the presence of an extended kinship network does not necessarily mean a larger pool of potential support from members of the household.

The literature on carers suggests that in most households, regardless of their ethnic background, care of an older person or someone with disabilities tends to fall on one person only, usually a woman. A few studies have reported that among Indian and Chinese parents there is a preference to be cared for by sons even though there are daughters available. However, it is the daughter-in-law who carries out the actual hands-on, direct physical care of the dependent relative. Several studies show that minority ethnic elders think that it would be unrealistic to have the same expectations of support in Britain compared to those they would have in their countries of origin.

There is a consistent body of empirical evidence that shows that older people would like to receive help with maintenance of the home and with basic domestic tasks when the ageing process makes it more difficult for them to carry them out independently. Several studies also mention access to transport and household adaptation as priorities reported by many older people. Studies that have looked at the provision of information and advice for older people have pointed out that many older people would like to receive more information about practical help and money benefits they may be entitled to and that they would like to be told where to get this information locally.

The literature identifies a number of ways in which services fail to meet older people's needs. These include examples of inequity, inadequacy and fragmentation of service provision. Examples of inequity consist of localities or groups with greater need that do not receive proportionally more services; variations in the type of services accessed by people with similar types of need; and variations in the range, type and quality of services offered by different local authorities. Examples of inadequacy consist of people who receive services that are not relevant to their needs or do not meet their needs in an effective, efficient or acceptable manner. Examples of fragmentation refer to both a lack of a holistic approach that coordinates health and social care services, and a failure to recognise the interactive nature of the needs of users and their carers, especially in the case of older people. A number of studies also mention that services tend to overlook older people's needs arising from short-term illness as well as their emotional needs.

Self-reported care and support needs

This study confirmed many of the findings in previous research on the views and expectations of older people regarding access to services. The study participants experienced increasing difficulties in performing household tasks that required strength and agility, and wished to receive some help with them. Family carers wished for

more coordination among different care providers to reduce pressure and their constant sense of responsibility. The study participants expressed a strong preference for accessing health and informational services locally and often reported lack of information about the availability and function of formal services.

Lack of attention to older people's emotional needs in service provision has been mentioned in previous research. However, there is a paucity of studies that specifically look at what emotional needs older people consider particularly important in caring relationships and whether these emotional needs differ among cultural groups. This study shows that all older study participants, irrespective of their cultural background, considered communication, understanding and trust as crucial for the establishment of effective and lasting relationships with both family carers and professional care staff. In particular, trust formed the basis for older people's and their carers' decisions about handing over those tasks that they could no longer do by themselves and for which they needed help.

Experiences and expectations of support from family, friends and neighbours

The findings of this study confirm that older people of minority ethnic background considered that it was unrealistic to have the same expectations of support in Britain compared to what they would have had in their countries of origin. Older Pakistani, Bangladeshi and Indian participants who lived together with their adult children stressed how busy their children were and how difficult it sometimes was to receive help from them. Cohabitation in a multigenerational household was not always the best solution for help and support. Some older Pakistani women said they wished they could leave highly stressful cohabitations with their daughters-in-law and live independently.

All study participants considered neighbours a good source of help in everyday life. A number of study participants even expressed a preference for involving friends and neighbours as paid carers. However, the participants were aware of the difficulties that the involvement of friends and

neighbours as formal carers might give rise to, for example in relation to food hygiene, financial issues and CRB clearance.

Experiences and expectations of support from health and social welfare services

This study supports the findings of previous research regarding the limits of service delivery to older people. Participants thought that, in recent years, the quality and extent of available services had become poorer. Many participants experienced very long waiting lists to have ramps and stair lifts installed. Lack of information was also often mentioned as a major source of frustration. Many reported that it was a burden to have to follow up much-needed services and information and as a result often missed out on services. Older people needed to receive information about available services at different points in time. Immediately after a health crisis, they often underestimated the impact of caring on their life. For many participants, buying help through the adult services department was a financial burden. Participants resented drawing from their savings to pay for services because they wanted to leave their life savings to their families.

There was a high expectation that service provision should respect basic professional and ethical standards ('good practice'). Participants complained that some care staff did not follow basic hygiene practices, such as using a dirty bowl to take clean water to wash the client or not washing their hands when visiting a new house. Communication and understanding of the views and personal caring preferences of older people and their carers were of paramount importance for a satisfactory and lasting caring relationship.

Conclusions

In conclusion, many of the issues that this study identified were not specific to Bradford, but reflected general issues and problems for older people and carers. However, most of the solutions to the issues raised could be found in Bradford.

There was a strong sense that services were run for the convenience and budgets of the service

providers rather than for the benefit of the service recipients. In addition, older people's individual preferences were felt not to be acknowledged because of a lack of understanding and sensitivity to the influence of lifetime experiences and cultural background.

Despite differences in background and cultural experiences, many of the needs described by the study participants were cross-cutting, relating to old age and specific life events, rather than to cultural, religious or ethnic influences. Older people and carers, therefore, shared many *general expectations* about help and support from services.

Many of the older people's *individual desires* and expectations related to their cultural and religious values and beliefs, as well as to their experiences in childhood and early adulthood.

It would seem that both general and specific individual expectations need to be satisfied in order for services to be acceptable and appropriate for older people. The development and application of cultural competency techniques may be a way for service providers to improve and promote culturally sensitive good practice throughout service organisations.

Although overt racism was only described in historical terms, some current practices and attitudes were (or could be) perceived as ageist and/or racist. However, some of the examples given to illustrate discrimination may have been more about lack of communication and lack of awareness of older people's expectations. In the light of findings from research elsewhere, and recent government targets, this seems to be an area that needs to be addressed.

Good communication was seen as key for developing trust and for creating awareness of older people's personal desires and preferences associated with their past histories, cultural and religious backgrounds. A major concern was the lack of effective communication between different service providers and between services and older people and carers. The provision of information about services was often not timely, which in some cases led to older people missing out on much-needed help and support. The lack of follow-up communication following benefit claims or requests for housing alterations caused frustration and sometimes led to alterations that did not meet older

people's expectations. The challenge of developing an effective and acceptable communication strategy needs to be addressed.

A desire for flexible and individually tailored services was evident across all groups, thereby supporting the government's proposals for Individual Budgets. Specific services that were mentioned included housing, 'meals on wheels' and home care. Older people wanted to have a say in how and where they lived, the quality of their food, and who provided 'that bit of help' in their homes.

The lack of flexibility and consideration of individual preferences had frequently resulted in older people and their carers choosing not to have a service because they considered it a waste of money. Service providers' approach to assessment and setting up care packages was described as 'ticking the box' rather than finding the best solutions for each individual.

Many participants displayed a surprising resourcefulness in overcoming the problems they faced. In some cases, this resourcefulness amounted to direct action, while in other cases pragmatic suggestions were made about to how the services could meet their expectations more directly, with many of their solutions based on local skills and resources.

1 Introduction

Background and context to the study

It is common knowledge that the number of older people in the UK is increasing. Currently, the population aged 65 and over accounts for 16 per cent of the total population in the UK and is predicted to continue to rise. The fastest increase in numbers is in the 'oldest old' group – those aged 85 years and over – who now represent over 2 per cent of the population (Dunnell, 2008). As a result, increasing government policy attention has been given to the implications of an ageing population for future services for older people (see, for example, DH, 2001, 2004, 2006; DfT, 2004; DWP, 2005; SEU, 2006). A recent example of the way services should be provided is the *Putting People First* document, which spearheads the government's personalisation agenda (DH, 2007). Under this initiative, local councils are expected to enable service users to have control over their own care and to have access to the services they want through devolved budgets. Although the principles of the personalisation agenda have for the most part been welcomed, there are concerns about the feasibility of its actual application both in practical terms and with regards to cost (Unity Sale, 2008) and, in particular, its applicability to older people (Glendinning *et al.*, 2008). Indeed, one of the challenges for future community services is the predicted increase in demand for health and social services as a result of the growing number of the 'very old' and, as a consequence, the increasing numbers of people with dementia and limiting longstanding illness (Dunnell, 2008).

In 2005, the government published *Opportunity Age* (DWP, 2005), which set out a number of proposals for policy change to enable older people to lead a full and productive life in the community. The main priorities identified by the document were to: increase employment rates and allow people aged 50 and over greater flexibility in their working lives; enable people to continue to play an active role in the community through the provision of adequate income, decent housing, accessible transport and opportunities for leisure, learning and volunteering; and enable people to maintain independence and control in later life.

A reduction of social exclusion among older people has been prioritised by several other government documents. The Social Exclusion Unit's report *A Sure Start to Later Life* (SEU, 2006) suggested a number of policy areas requiring attention to ensure social inclusion among older people, including better access to services and information, joining up services, user involvement, advocacy, increasing the capacity of services and preventive services. Likewise, the *National Service Framework for Older People* (DH, 2001), *Tackling Health Inequalities* (DH, 2003) and *Our Health, Our Care, Our Say* (DH, 2006) set out ambitious targets for care across health and social services and for a reduction in inequalities through improved income, social housing and access to services.

Many of these strategy and policy documents have drawn on research that has explored the views of older people and their carers regarding their expectations and experiences of services. However, despite such research there are still gaps in our knowledge about older people's experiences and perspectives regarding services they receive and access to services they might desire to receive. There are two main reasons for this: first, older people have frequently been treated as a homogenous group and, second, some groups have been over-researched while others have remained ignored. A number of UK studies have explored older people's views about their health, housing or support needs, and experiences of service use (see, for example, Horne and Costello, 2003; Godfrey *et al.*, 2004; Older People's Steering Group, 2004; Barrett, 2005; McCann *et al.*, 2005; Heenan, 2006; Raynes *et al.*, 2006; Clough *et al.*, 2007) and investigated the experiences and perceived health and support needs of carers (e.g. Seabrooke and Milne, 2004; Seddon *et al.*, 2004; Jarvis *et al.*, 2006). However, despite the wealth of research in this field, the needs and preferences

of some groups of minority ethnic older people and their carers have continued to be ignored (Ahmed and Jones, 2008; Chahal and Temple, 2005; Katbamna *et al.*, 2004; Merrell *et al.,* 2005). In addition, we might ask ourselves how much of the knowledge we now have has actually been implemented in practice.

Bradford

These government strategy documents have sparked off a range of local initiatives, including in Bradford, where local targets include: to reduce health inequalities and increase life expectancy; for all older people to promote well-being in older people so that they can play a full part in the civil society of Bradford; for dependent older people to improve the quality of life (Bradford Metropolitan Council, 2007, pp 55–6). However, in a review Darlow *et al.* (2005) noted a general lack of studies on issues of social care in Bradford, while existing research was criticised for being too focused on specific ethnic communities (Pakistani, Bangladeshi, Indian) to the exclusion or under-representation of others (Chahal and Temple, 2005; Darlow *et al.*, 2005). This may have resulted in insufficient attention given to issues facing other sections of the community, including groups within the white population. The reports suggested that there was a need for further in-depth research in this field, taking into account the individual needs of elders and carers in different ethnic communities at a local level in Bradford. Indeed, one of the dilemmas for service providers in Bradford has been the uncertainty of not fully understanding the experiences, needs and preferences of older people and their carers with regards to health, social welfare and other services (Outside Research and Development, 2006).

Purpose of the study, aims and objectives

This study set out to explore the views of older people and their carers from a range of ethnic communities within Bradford in relation to their needs and experiences of care and support. In particular, the intention was to address two central areas of government policy and practice: the accessibility and acceptability of services to older people and their carers and the barriers and facilitators to the take-up of services, such as language, cultural appropriateness, awareness, affordability and perceptions of services. This study was about older people first and for most. The carers in the study were either individuals who cared for older people or were older people themselves.

The aims were:

- to identify the needs, views and perceptions of older people, their families and carers in Bradford regarding current care provision and future aspirations;

- to identify the extent to which older people, their families and carers consider that their care and support needs are, or might be, met and by whom.

The objectives were:

- to explore the commonalities and differences in care and support needs across and between specific groups of older people, their families and carers in Bradford;

- to explore perceptions of the accessibility and acceptability of services and support, in relation to information and advocacy needs, and potential or actual barriers to the take-up of services;

- to gain an understanding of the key issues for the development of culturally sensitive services relating to housing, social care, community support and health;

- to identify gaps in local services for older people and their carers with regards to access, coordination, funding, capacity building, development and so on.

Definitions and debates

A number of terms and expressions were debated and agreed before the fieldwork began. The most important of these were 'support', 'informal and formal carers' and 'ethnicity and culture'.

Support

Most people have some notion of what is meant by 'support' and the literature abounds with theories about social support, social networks, social bonds and so on. While it is not possible to outline the full range of theories or debates in the field here, they all suggest some form of positive interaction or helpful behaviour directed at a person in need of support. The definitions of support have been summarised into five categories: the type of support provided; the recipient's perceptions of the support provided; the intentions or behaviours of the provider of support; reciprocal support; and social networks (Hupsey, 1998).

The availability of support through interactions with family and friends and/or formal services and the perceptions of that support could be said to be particularly relevant with regards to minority ethnic older people because of two dominating and contrasting views: that minority ethnic groups tend to 'look after their own', and that minority ethnic families are in crisis due to the influence of migration on where people live and because of changes in family structures. The first view implies that formal support is not needed because care is provided by the extended family system, the second that minority ethnic communities are unable to support their dependent elders and therefore require a range of formal services and support. That said, an understanding of the availability of formal and informal support for all older people, and particularly of their perceptions of that support, is required to be able to develop and provide services that are appropriate and acceptable for older people.

Informal and formal carers

The study explored older people's perceptions of both informal and formal care. Based on the Carers Organisation's (The Princess Royal Trust for Carers, 2005) definition, an (informal) carer was viewed as someone who provides unpaid care for family members, friends or neighbours who could not manage without their help because of age, illness, disability or addiction. A (formal) paid carer was defined as someone receiving payment for the care they provided, such as care workers, care assistants, home carers or nurses. Throughout this report, we use the expressions 'carer' and 'care staff' to denote the differences.

Ethnicity and culture

Initially, we decided to use Bulmer's (1996, p 35) definition of a minority ethnic group as 'having real or putative common ancestry, memories of a shared past, and a cultural focus upon one or more symbolic elements which define the group's identity, such as kinship, religion, language, shared territory, nationality or physical appearance'. However, it soon became clear to us that the concepts of 'ethnicity' and 'culture' were often but not always overlapping. This became particularly obvious in the analysis of the interviews, where older people frequently talked about their 'culture' without necessarily referring to their 'ethnicity', which led us to debate whether or not Bulmer's attempt to merge ethnicity and culture was actually helpful.

The World Health Organization suggests in *Active Ageing: A Policy Framework* (WHO, 2002) that cultural values and traditions underpin all other determinants of 'active ageing', thereby shaping the way a given society views older people. It would seem that definitions by 'ethnic groups' are labels or categories given by surveys such as the Census or government departments to describe particular (minority ethnic) population groups. As such, they are frequently debated and changed. Cultural values and norms on the other hand are described as social factors that influence the personal environment (along with other social factors). Interestingly, in the introduction to the Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC) survey, the difficulties of carrying out mental health surveys related to ethnic differences are mentioned because of the cultural differences in the way people experience and express mental health (Sproston and Nazroo, 2002). For the purpose of this study, we concluded that although our sample was selected from specific 'ethnic groups', the issues that the study explored in relation to experiences, perspectives and expectations of support and services were mostly to do with 'cultural values and norms'.

The importance of this distinction is that research suggests that people from minority ethnic groups are less likely to use health and social care

services and are less aware of what help is available (Yeatts *et al.*, 1992; Boneham *et al.*, 1997; Bowes and MacDonald, 2000). This may be because black and minority ethnic groups often feel that services are not appropriate for their needs. In addition, in some cases older minority ethnic people feel detached from their own community as well as from mainstream society (Yu, 2000a; Rai-Atkins, 2002a; Chalal and Ullah, 2004).

Geographical location and relevant demography

In 1801, Bradford was a small rural market town with a population of 6,393. Thirty years later, thanks to the booming textile industry, the population was 97,191 and by 1851 it had increased again to 181,964. By 1902, Bradford was becoming multicultural with 23 of 36 yarn merchants being German along with 31 of the 63 piece merchants. In the first half of the 20th century, thousands of Italians emigrated to Bradford and, after 1945, Austrian, Byelorussian, Estonian, Hungarian, Jewish, Latvian, Lithuanian, Polish, Ukrainian, Yugoslavian and more German immigrants added to Bradford's ethnic mix to find work in the mills. During the 1950s, Asian and African Caribbean immigrants arrived in Bradford from Bangladesh, Barbados, Dominica, East Africa, India, Jamaica, Pakistan and smaller islands, including St Lucia and St Kitts (Bradford Metropolitan District Council, 2008).

The 2001 Census showed about 22 per cent of the population reporting to have a 'non-white' background, of which 15 per cent were Pakistani, 3 per cent Indian, 1 per cent African Caribbean, 1 per cent Bangladeshi and 2 per cent other. In addition, the number of people with limiting longstanding illness had increased by 5 per cent from the previous Census, while the proportion of carers mirrored national figures (Bradford Metropolitan Council, 2003). This can be compared with the national picture of the UK where 92 per cent report to be 'White British', 1.8 per cent Indian and 1.3 per cent Pakistani (National Statistics, 2003; Dunnell, 2008). Young people make up a larger proportion of the population of Bradford compared with national figures. However, the workforce is getting older and the number of people

aged 75 and over is increasing. This will in the future have implications for care services.

Methods

The project had two distinct stages: (a) a literature review and (b) the data collection, analysis and synthesis. The data collection consisted of a two-pronged approach using focus group interviews and in-depth interviews.

Literature review
The purpose of the literature review was to provide a context for the fieldwork stage. It considered approaches to successful engagement with older people and minority ethnic groups, and the specific needs and aspirations of older people from minority ethnic communities.

Focus group interviews
Focus group interviews were undertaken with groups of older people and carers from ten ethnic communities: African Caribbean, Bangladeshi, Hungarian, Indian, Irish, Italian, Pakistani, Polish, Ukrainian and White British. The purpose of the focus groups was to enable older people and their carers to explore general issues relating to service provision in a non-threatening environment. They also provided an opportunity for participating older people and carers to get to know and trust the research team, which helped in the exploration of personal and often sensitive experiences in the in-depth interviews. All interviews were conducted in a familiar location, such as a community centre or a local project and were tape recorded with the interviewees' consent. A total of 21 focus group interviews were undertaken with groups varying in size from 3 to 21. The total number of older people interviewed was 137 and carers 33. A breakdown by age, gender, location, and ethnicity of the study participants can be found in Appendix 2. Case studies, in the form of vignettes, were used to stimulate discussion and to ensure understanding and articulation of the issues being explored. We found that older people were more likely to express their personal needs and desires if hypothetical cases based on familiar situations were presented to them than if they were asked to consider something that seemed more abstract.

In-depth interviews

In the second stage of the data collection, in-depth one-to-one interviews were undertaken with a sample of 38 older people and 15 carers. These were partly identified through the focus groups and partly newly recruited on the basis of their self-reported care needs and current or past experiences of social care services. The purpose of the interviews was to give interviewees an opportunity to talk through their lives (narrative approach), while reflecting on their contacts with and experiences of a range of services, such as health, community support, social care and housing. This enabled exploration of the 'caring period' as well as the transitional time preceding caring for/being cared for. In some cases, older people's experiences related to experiences outside the UK and helped to ground perceptions of current services, needs and aspirations within their cultural framework. Interviews were tape recorded with the interviewee's consent.

A detailed description of the data collection, sampling and analysis is provided in Appendix 1.

Interpreters

Sixteen interpreters were engaged for the duration of the fieldwork for the following languages: Bangla, Gujarati, Hungarian, Italian, Polish, Punjabi, Ukrainian and Urdu. To ensure that we shared a common understanding of research practice, roles and responsibilities, needs and expectations, a two-day training event was organised before the interviews commenced. A detailed description of the training workshops is provided in Appendix 3.

Organisation of the report

Following a summary overview of the literature review in Chapter 2, the findings are presented in Chapters 3 to 5 under the themes identified through the interviews: care and support needs; experiences and expectations of support from family, friends and neighbours; experiences and expectations of support from health and social welfare services. Chapter 6 draws together the main findings and discusses the main policy and practice implications of the findings.

2 The research literature: an overview

This project included a full review of the literature on the specific aspirations and needs of help and support of older people of minority ethnic background, which has been written up as a separate document and is available on request from the authors. Here, we present a summary of the main findings from that review in four sections:

- the availability of sources of care and support among older people and carers of minority ethnic background;

- expectations of care and support from informal and formal sources of help among older people of minority ethnic background;

- unmet needs of older people;

- relevant issues for the development of culturally sensitive services.

The availability of help and support among older people and carers of minority ethnic background

A small number of studies have investigated the demographic and socioeconomic factors that can affect the extent of the pool of potential support available to older people of minority ethnic background. Blakemore (2000) used Census data to show that in 1991 the Bangladeshi community and the Pakistani community had a high child dependency rate. He pointed out that this may impact on the support capability of their middle-aged cohorts of family carers, as these have to care at the same time for both old and young dependants. The Indian community, on the other hand, had a significant lower dependency rate overall when compared to the White British majority.

In 1991, most minority ethnic families in Britain had still very few older relatives to look after compared with the White British majority (Blakemore, 2000). While almost 20 per cent of the White population was over retirement age, only 6 per cent of the African Caribbean, 4 per cent of the Indian, 2 per cent of the Bangladeshi and 1 per cent of the Pakistani populations were over retirement age. Because immigration from the Caribbean peaked in the 1950s, there was a large group of African Caribbeans in their late fifties or early sixties in 1991, compared with other minority ethnic groups. Although these phenomena seemed to imply an ability of this group to assume much of the responsibility for their own care in later life, Blakemore (2000) highlighted three factors that may affect the experience of care and support self-sufficiency within the African Caribbean community:

- evidence of poor health among late middle age/early old age groups of African Caribbean people;

- a considerable proportion of African Caribbean people living alone, which raises the risk for social isolation;

- the risk that the African Caribbean community shifts 'from being a cohort group with an excess of potential carers to a cohort group with rapidly increasing care needs' (Blakemore 2000, p 24), because the demographic bulge of the migrant generation of the 1950s and 1960s from the Caribbean was quite tightly compressed in terms of time.

Research shows contrasting findings with regard to whether minority ethnic groups are more or less likely to live on their own compared with the White majority. Butt *et al.* (2003) stressed that in their study with 203 older people from Caribbean, Asian (including Chinese), African and White communities aged 55 and over, more than half of

Black Caribbean and Chinese participants lived in single-person households. On the other hand, Karn *et al.* (1999) point out that the 1991 Samples of Anonymised Records (SARs) data showed that minority ethnic elders (over the age of 65) were much less likely to live alone or just with a spouse compared with older White people. Only about 20 per cent of Bangladeshis and Pakistanis, 34 per cent of Indians, 43 per cent of Chinese and 61 per cent of Black Caribbeans lived alone or just with a spouse, whereas the figure for the White population was 84 per cent.

According to Fenton (1987), men will outnumber women among Black older people because of the differences in migration patterns. The gender imbalance in the older population can lead to a higher number of people living alone in later life and, therefore, being at a higher risk of loneliness and isolation. This is opposite to the situation among the White population. However, considering that migration patterns differ across minority ethnic communities, more research is required to investigate the impact of gender differences on the caring dynamics in each minority ethnic group.

Expectations of care and support from informal and formal sources of help among older people of minority ethnic background

Qureshi and Walker (1989) and Finch and Mason (1990, 1993) proposed the concept of a 'hierarchy of obligations' to explain older people's preferred sources of support. According to this theory, the primary basis of social support springs from spousal and parent–child relationships. If these relationships are not available, then other subjects, including public services, might assume supportive roles. Sin (2006, 2007) investigated the hypothesis that people's expectations of one type of support are affected by their experiences or expectations of other sources of support. The author reported three main findings:

- Asian-Indian respondents showed a high level of expectation for family support, which coexisted with a high level of expectation for state support.

- Proportionally more Asian-Indian respondents mentioned the state as an expected source of support in comparison to the White British respondents. However, the White British sample had a larger proportion indicating that the state is their first option.

- The preference of older people for formal and informal sources of support need not be mutually exclusive. The majority of the Asian-Indian and White British participants interviewed by Sin (2006) said that they would like to use one or more of the public services available at some stage, regardless of their current use of public services and of the quantity and quality of informal support they received.

A number of studies have reported a larger proportion of multigenerational households among South Asian groups such as Bangladeshis, Pakistanis and Indians, even though there is evidence that the proportion of such households among Indians has been decreasing (see, among others, Blackmore, 2000; Evandrou, 2000; Butt *et al.*, 2003; Burholt, 2004). However, findings from empirical research have shown that the presence of an extended kinship network does not necessarily mean a larger pool of potential support from members of the household (Phillipson *et al.*, 2000; Chiu and Yu, 2001; Katbamna *et al.*, 2004; Merrell *et al.*, 2005). For example, Chiu and Yu (2001) explored the capacity of multigenerational households of Chinese immigrants in Britain to meet the needs of their dependent elders. They showed that, on the one hand, living in a multigenerational household increased the capacity of older people to receive help with the maintenance of the home and with domestic tasks. On the other hand, long working hours and shift-work routines affected the capacity of households to satisfy the self-care needs and the social and emotional needs of their older dependants. Chiu and Yu (2001) concluded that the older Chinese participants had many relevant needs unattended and that the idea of self-sufficiency of care in Asian communities was unfounded. In a study of 100 Chinese older people set in South Yorkshire, London and Glasgow, Yu (2000b) reported that many older Chinese participants were isolated

from both the Chinese community and mainstream society. Sixty-five per cent of the study participants thought that they were seen as 'useless' and 'burdens' because they no longer made any contribution to society and their family. About 55 per cent felt a little sad or very sad most of the time.

A few studies have reported that among Indian and Chinese parents there is a preference to be cared for by sons even though there are daughters available (see Spitzer *et al.*, 2003; Sin, 2006). However, it is the daughter-in-law who carries out the actual hands-on, direct physical care of the dependent relative (Adamson and Donovan, 2005). In contrast, African Caribbean parents mostly expect a daughter with whom they have shared a household for a longer period of time to care for them (Adamson and Donovan, 2005). Several studies show that minority ethnic elders thought that it would be unrealistic to have the same expectations of support in Britain compared to what they would have had in their countries of origin (Neufeld *et al.*, 2002; Katbamna *et al.*, 2004; Sin, 2006, 2007).

Moffatt and Higgs (2007) explored the beliefs and discourses on which rights to welfare benefits are constructed in later life in a study of people aged 60 and over in North East England. They highlighted how successive UK government agendas towards welfare involved a shift from citizen to consumer. By drawing on the work of Bourdieu (1990), they argued that the failure of some older citizens to operate as citizen consumers can be explained in terms of a generational welfare 'habitus'. The concept of 'habitus' refers to a system of acquired schemes of perception, thought and action that is developed in response to structural factors, such as class, family, and education, and the external environment (Bourdieu, 1977).

Raynes *et al.* (2001) investigated older people's views about what makes a quality home care service. Important points included:

- receiving help with maintenance of the home and receiving help with basic domestic tasks such as changing light bulbs, cleaning windows and washing curtains;

- having access to aids and adaptations such as grab rails, ramps, level-access showers, and stair lifts;

- having access to transport and other assistance that enables them to get out and about.

Raynes *et al.* (2003) examined current practice in the provision of information and advice for older people through a literature review, an analysis of the websites of three major providers, and focus groups. They showed that older people valued face-to-face contact in the provision of advice and that it is important to involve them in the design, production, dissemination and monitoring of information. Quinn *et al.* (2003) interviewed 13 older people in depth and held group interviews with over 100 older people in different community settings across Slough (Berkshire). They reported that older people saw information as a means to an end, not an end in itself. Information was not valued if it did not lead to a service or a solution to a problem. The concept of advocacy was not recognised among older service users, particularly among older members of South Asian communities, as the term 'advocacy' has no exact equivalent in Asian languages.

A nationwide survey to determine the support and information needs of older people and disabled older people in the UK showed that substantial numbers of the respondents experienced difficulties with everyday tasks and with accessing the information they needed (Barrett, 2005). Over 40 per cent of all respondents (more than 1,630 questionnaires were completed) wanted more information on:

- home adaptations and useful equipment;

- who to contact for advice on money matters.

Over 50 per cent of all respondents wanted more information on:

- practical help they may be entitled to;

- money benefits they may be entitled to.

Over 70 per cent of respondents said that they would like to be told where to get this information locally.

In a review of research on minority ethnic older people, Chahal and Temple (2005) highlighted a number of key findings:

- the housing needs of 'White' and 'Black' refugee communities, which were ignored in the literature;

- the importance of investigating housing needs at a local level with local community groupings;

- the dangers of over-researching established minority ethnic groups, who feel they have been 'researched to death' (Butt and O'Neil 2004), and ignoring the needs of smaller minority ethnic communities that become 'invisible' to the system;

- the need to undertake research with a methodological approach qualitatively different from the current ones. A wider range of minority ethnic communities should be taken into consideration and they should be approached 'as dynamic and evolving entities all of whom occupy different class, gender, age and religious positions' (Chahal and Temple, 2005, p 36);

- the need to focus research on housing provision for older people on the knowledge of local housing markets, older people's social and care needs, and their life histories in relation to housing and to the neighbourhood in which they live.

Unmet needs of older people

Godfrey and Callaghan (2000) identified three main ways in which services fail to match the needs of older people as defined in the community care policy:

- because of inequity, in other words those cases in which:

    - localities or groups with greater need did not receive proportionally more services;

    - there were variations in the type of services accessed by people with similar types of need; and

    - there were variations in the range, type and quality of services offered by different local authorities.

- because of inadequacy, in other words those cases in which the services that people received were not relevant to their needs or did not meet their needs in an effective, efficient or acceptable manner. Two main factors were deemed to cause inadequacy:

    - needs assessment carried out only on subjects considered at risk, where risk is defined in terms of severity of disability and lack of availability of an informal caregiver. This approach was found to affect not only people's eligibility to services, but also the nature of the assessment and the extent to which the caregiver needs were addressed;

    - a lack of attention to the emotional components of need as well as to the investigation of the perception of dependency of older people. The assessment systems and practices were found to be dominated by a focus on physical and mental impairments. However, the authors pointed out that these may not in themselves predict need for care. For example, research on the factors influencing admission of older people to residential care (DH, 1994; Groger, 1994) showed that the sheer determination not to go into care, rather than the level of impairment, was the key factor to discriminate between those who remained at home and those who were admitted.

- because of fragmentation, meaning a lack of a holistic approach that coordinates health and social care services, and a failure to recognise the interactive nature of the needs of users

and their carers, especially in the case of older people.

Cordingley *et al.* (2001) reported a number of overlooked needs of older people. These included:

- needs arising from short-term illness, which are overlooked by a policy discussion mainly centred on long-term support needs. These needs mainly affect childless and unmarried older people;

- the emotional needs of older people who care for their spouses or partners. For example, the emotional and social needs of older women caring for their husbands are often not met. Being married may create expectations in others that such needs are met, whereas the caring commitments may jeopardise the social activities married women once enjoyed;

- the needs of older people afflicted by loneliness, isolation and depression;

- the needs of a same-sex carer.

Tanner (2001) stressed that people's 'felt' needs are translated into requests for services on the basis of their expectations about what agencies can and should provide, about what is legitimate to ask for and, finally, their knowledge of what is or is not available to them (see also Godfrey and Callaghan, 2000). Through a literature review of older people's perceptions of independence, Tanner (2003) highlighted the importance of social needs such as to keep physically, mentally and socially active for older people. Nevertheless, those needs are likely to be given scant consideration in needs assessments carried out under the current community care policy, as these are mainly preoccupied with the management of daily living activities. Tanner (2003) argued that more attention needs to be paid to ensuring that older people access services that are:

- in accordance with their own perceptions of need;

- support their own problem-solving efforts;

- are provided in a way that sustains a positive sense of self.

A number of studies have highlighted how people from minority ethnic groups are less likely to use health and social care services and are less aware of what help is available (among others, Yeatts *et al.*, 1992; Boneham *et al.*, 1997; Bowes and MacDonald, 2000). Yeatts *et al.* (1992) distinguished between three types of barriers that were associated with perceived need for service and service use:

- 'lack of knowledge' barriers, which referred to the knowledge of older people about service availability and procedures as well as to the acknowledgment of their own needs for help and support;

- 'lack of access' barriers, which referred to factors such as transport, affordability and, in the case of minority ethnic elders, language barriers;

- 'lack of intent' barriers, which referred to the acceptability of services.

Scheppers *et al.* (2006) presented a comprehensive literature review of studies carried out in different countries and among different minority ethnic groups about the potential barriers and factors that may restrict minority ethnic patients from using health services. Potential barriers were identified at three levels:

- patient-level barriers, which were related to patient characteristics, e.g. age, gender, ethnicity, lifestyle, etc;

- provider-level barriers, which were related to provider characteristics, e.g. communication style, skills, medical procedures and practices, translation, etc;

- system-level barriers, which were related to the organisation of the healthcare system, e.g. referral system, medical paradigm, organisational factors, etc.

Some of the barriers were tied to minority ethnic groups. However, all of the barriers were entangled to the particular situation of the individual patient and subject to constant adjustment. The authors, therefore, concluded that generalisations were not possible.

Relevant issues for the development of culturally sensitive services

Katbamna *et al.* (2001) proposed a seven-point evidence-based guideline to assist primary healthcare teams (PHCTs) in their work with carers within South Asian communities:

(1) Members of PHCTs should communicate with carers in a form which carers can understand.

(2) Carers should have access to information about the full range of services offered by the PHCT.

(3) Team members should acknowledge the role played by informal carers in providing care for sick and disabled people.

(4) The team should know which of its patients are carers.

(5) Members of PHCTs should be aware of the range of services other members of the team are able to offer to carers.

(6) Carers should be treated as individuals in their own right, their individual needs being recognised with regard to cultural and religious beliefs.

(7) A basic patient-held continuing record should be kept at the disabled person's home to facilitate the coordination of care provided by different health professionals.

Although many of these guideline recommendations can be applied to support all carers, irrespective of their ethnic background, Katbamna *et al.* (2001) stressed the importance for PHCTs to recognise the particular needs of South Asian carers.

Brach and Fraser (2000) discussed the potential role of sound cultural competency techniques in delivering health services to reduce racial and ethnic health disparities. The concept of 'cultural competency' implies moving beyond simple campaigns aimed at promoting cultural awareness or sensitivity in service provision towards an 'ongoing commitment or institutionalisation of appropriate practice and policies for diverse populations' (Brach and Fraser 2000, p 183). The authors identified nine major cultural competency techniques in the literature:

- interpreter services;

- recruitment and retention policies;

- training;

- coordinating with traditional healers;

- use of community health workers;

- culturally competent health promotion;

- including family/community members;

- immersion into another culture;

- administrative and organisational accommodations.

Brach and Fraser (2000) emphasised that although there was a significant body of research on cultural competency techniques to overcome language barriers, there was a dearth of rigorous research evaluating the impact of all the other cultural competency techniques on any outcomes, including the reduction of racial and ethnic disparities. The authors called for more studies on the comparison of culturally competent interventions with interventions uninformed by patients' language and culture. This would help to clarify the role of confounders such as education, literacy and class as causes for racial and ethnic disparities. It would also help to identify which cultural competency techniques are effective and how to implement them properly.

Rai-Atkins (2002b), in a study that involved over 250 people, suggested a number of steps that may help mainstream advocacy networks and local advocacy providers to promote culturally sensitive services:

- Make explicit commitments to sharing resources, expertise and access to decision-making with black projects, service users and carers.

- Encourage black service users and their carers to define their own needs and act upon these definitions.

- Listen to and understand what black service users and carers are saying.

- Transform themselves into services that genuinely meet the needs of all communities.

- Patient and user-led forums should represent minority membership. This may require local capacity building in voluntary and community organisations to enable a meaningful two-way process of engagement.

In a qualitative investigation of the challenges implicit in the development of 'culturally competent' palliative care for South Asian cancer patients, Owens and Randhawa (2004) suggested that it is necessary to move beyond rigid views that see needs as either exclusively culturally based or universally valid. They and Katbamna *et al.* (2001) emphasised the importance of providing care on an individual basis whatever the person's background.

Overview

This literature review has shown that the belief that minority ethnic groups are self-sufficient in terms of care of their elder dependants is unfounded. It has also identified some of the cultural and religious dynamics that frame older people's and carers' expectations of support. The existing literature emphasises the need to study the diversity of minority ethnic groups and to address the differences that can emerge at a local level within the same ethnic group. Although there is

a growing body of literature around Asian, South Asian and African Caribbean elders in the UK, there is a lack of research on White European minority ethnic communities. Overall, the literature strongly indicates the need, at a policy level, to translate research findings into action.

3 Self-reported care and support needs

This chapter describes the study participants' self-reported needs of care and support. These have been categorised into four main themes:

- instrumental support needs;

- emotional needs;

- informational needs;

- translational needs.

The expressions 'instrumental support needs', 'emotional needs' and 'informational needs' describe three types of people's actual and perceived social support (Helgeson, 2003) and refer to people's experiences of:

- concrete help and assistance, such as help with household chores, lending money or running errands;

- the availability of people who can listen, care, sympathise, provide reassurance and make one feel valued, loved and cared for;

- the provision of information or guidance.

The expression 'translational needs' refers to specific language needs that emerged from the interviews with the study participants of minority ethnic background.

Instrumental support needs

Older study participants consistently talked about their increasing difficulties in performing household tasks. Difficult household activities were those that required strength and agility, for example lifting mattresses, carrying washing, cleaning windows or underneath furniture, vacuuming, climbing ladders, changing light bulbs, gardening and house repairs.

A certain type of cleaning you can do yourself, but when you get older you can't get down to clean the cooker because you can't get back up again.
(Ukrainian woman, 79, living alone)

People living in terrace housing now they find that they have to put washing for drying in the cellar and they can't go down the steps or up the steps. So my wife has to do all these things. Gardening is out of the question, I can't manage to sit down or do the gardening myself, but we manage just to buy some pots and put them outside.
(Pakistani man, 78, living with wife)

In my own house I have big windows, I can't clean them anymore.
(Italian woman, 69, living alone)

I can't make beds, I can make the bed but I can't lift the mattress. Things like that, anything that involves lifting, carrying, I can't do.
(White British woman, 80, living with husband and adult son with learning difficulties)

Some older people in their seventies and eighties and older people with health problems reported difficulties with more basic household chores, for example:

I would like to cook but I can't stand for a long time, only half an hour or something and then I want to sit down, I can't stand, so it's very difficult for me to cook.
(Indian woman, 74, living with husband)

A Pakistani woman caring for both her ageing parents mentioned their struggle with pushing the rubbish bin outside for collection:

I think it would sometimes be helpful if there could be a volunteer or someone, because I know sometimes my parents struggle even to put the bins out. The bin men come very early in the morning and because they are both very elderly it's just pushing the bins through the passage to get to the footpath, they find it difficult.

(Pakistani female carer, 41, living with her own family)

Older study participants often talked about 'other' older people who were isolated and did not have family or a family that lived close to them. In their view this group of older people was particularly vulnerable, because they would require a lot of help if their health suddenly deteriorated. These older people were often thought to be unknown to service providers and might therefore not have direct access to any help in case of an emergency. The following extracts exemplify these fears.

He lives alone, if he falls ill there is no one to look after him, if he needs the telephone, who is going to call him the doctor? If he is lying in his bed, who is going to help him get to the toilet? If he wants to eat something, who is going to help him get the food?

(Bangladeshi older man, 75, living alone, through interpreter)

I was a very happy person until last September. When I came back from [overseas] I had very bad arthritis symptoms. If I didn't have my wife I would have no help at all. My situation was such that I couldn't even pull the cover of my bed, which was very light. In those cases you need somebody around you. If we are both stuck in the bedroom, what would happen to us? I can't get out of my bed, my wife can't get out of bed, we are both lying in our separate rooms.

(Indian older man, 80, living with wife)

Family carers worried about 'what if something should happen' and emphasised the importance of coordination and continuity of support available to older people. The coordination was seen as an important source of help that could reduce the pressure and constant sense of responsibility

that carers experienced in their everyday life. This issue is exemplified in the view of a 56-year-old Polish woman who cared for her father who had Alzheimer's disease:

I had breakfast with my dad today, I left him in and he will still be in bed when I get back and I will make him another meal. But if I knew that in between time somebody [the doctor, the chemist] goes in and sees if he is all right. It makes me feel comfortable to know that my dad will not be on his own for eight hours, so that I am not stuck in the traffic wondering if he has had anything to eat and I wonder if he is alright. Knowing that puts less pressure on me.

In summary, the instrumental support needs reported by the study participants were mainly related to:

• physical and health needs linked to the ageing process;

• social isolation through a lack of or a reduced number of contacts and interaction with a wider social network;

• the type of house in which they lived, for example, terrace, flat, etc.

Notably, access to 'that bit of help' (as described by Raynes *et al.*, 2006) with everyday tasks was not only clearly linked to study participants' capacity to live independently, but often also to their capacity to satisfy emotional and social needs.

Emotional needs

Our analysis found that participants' experiences of help and support were often strongly linked to a number of psychological factors, feelings and wishes, in other words emotional needs. Although all individuals have emotional needs, these can increase during periods of excessive stress, physical and mental illness, and also in specific stages of life, including old age. The study participants often stressed the importance of anticipating and satisfying these emotional needs when receiving care and support both from family

carers and from professional care staff. Failing to take into consideration emotional needs in caring relationships was often the basis for difficult relationships with both formal and informal carers and for dissatisfaction with the help received.

Three emotional needs were particularly important to respondents in relation to receiving care and support:

- communication with carers;

- trust;

- relief from loneliness.

It is worth noting that the importance of these three emotional needs for caring relationships was recognised across all the ethnic groups involved in the study. This shows that the study participants had a significant element of similarity despite their different backgrounds. However, our analysis also shows that:

- This similarity in the participants' views did not necessarily imply a similarity in their preferences for how services should respond to their emotional needs. This suggests that older people's cultural, spiritual, mental health and physical health characteristics need to be taken into consideration when addressing their emotional needs.

- Older people should not be treated as if their emotional and psychological needs are all the same in nature or in degree; specific subgroups of older people, for example widowed women and men, may have more intense or more specific emotional needs.

Communication with carers
Older people talked extensively of the importance of having clear and ongoing communication with their sources of help about their personal preferences and support needs. To be able to share a common language with care staff was important for clear communication, particularly for those who did not speak English well. However, views about communication did not refer only to the question of language barriers. Awareness and responsiveness

to older people's personal caring preferences and individual backgrounds were also necessary to establish effective communication and a lasting caring relationship, illustrated by the following examples.

She is saying that it's best if the carer can communicate with her, this is very important. So, the carer asks 'is she okay?' 'Does she need anything else?' Then she will receive good service from her and if the language is a problem they can always get an interpreter or some kind of help and can come around the language barrier. And that is how the service will be better.
(Bangladeshi woman, 65, living with extended family, through interpreter)

Yes language is important. If [somebody's] language is not good and she doesn't talk English then yes, she needs somebody with whom she can talk, she needs somebody Pakistani who can think of the hard words she wants to say. Otherwise she will be confused, what she wants to say she can't say. It will be more difficult for her, then she will say, no don't come, I'm ok myself.
(Pakistani woman, 61, living with husband)

Mostly people need people from the community, friends or relatives or something like that. Then they can, you know, trust them as well, they can speak their own language, they can tell their problems.
(Pakistani man, 63, living with extended family)

The participants' personal background and experiences frequently influenced their choices and decisions about help and support. For example, older White British participants mentioned that their parents' generation often did not like to receive help from non-family members. They argued that these attitudes and expectations had to be recognised when planning and providing care and support for this group of much older people.

My mother was like that, she didn't want any strangers come in at all, she didn't even want the carers.… My dad was ill and he had to have

the nurse three times a day to see to him and she didn't even want them. It right upset her. I used to have to stop at night until they came so that she could go to bed before they came. … My mother's age group were all sort of family things like that and they didn't go out that much. Our generation mix more, so you might have in years to come like us we won't do that.

> (White British older woman, 68, living with husband)

On the other hand, Polish carers said that their parents' experience of never having cared for their own ageing parents, as they were left in Poland, together with their experiences of occupation and deportation during the Second World War, shaped their expectations of care and support in old age in two ways. First, their parents expected to receive support and company from their children at all times during the day. Second, their parents did not want any external help, as they had often developed a strong fear of 'officers' as a consequence of their experiences during the Second World War.

My mum doesn't want any help. If there were two of me and one could be with mum all the time and the other person who does their own thing all the time that would be great, but mum only wants me. I'm going away this weekend to visit my two kids and the thing she says is 'Who's going to look after me?', but in Polish. When I am going away she will say 'Do you have to go?' and I say 'well mum, I have to go, I have got a husband who has taken early retirement so that we can have time together!', then she says 'I don't want anyone coming to this house!'. So really she wants me all the time.

> (Polish carer, 56, living with husband)

When the mail came and my parents saw a brown envelope they were used to be terrified because they thought 'who is it?'. My mother, even today, she is eighty-three, she thinks that at some point they are going to be sending her back to Poland and she has nowhere to go, as her village no longer exists. They are frightened of bureaucracy; assessments on them to see what they have got, how are they going to manage, it smacks of bureaucracy….

> (Polish carer, 54, living with husband and mother)

The experience of long-term illness was also given as a reason for older people's expectation to have their adult children on hand all day.

My mother is totally absorbed in herself, now I have seen this amongst a lot of elderly people that I have looked after. I think it is quite common to people who have a long-term illness, be it acute, chronic illness where they are actually feeling it.… It's English as well, it is a common factor….

> (Polish carer, 54, living with husband and mother)

Ukrainian carers reported similar views and experiences. However, one carer described how growing up in an environment where there were no older people, because her parents were the first generation of immigrants, had influenced her own expectations and attitudes towards caring.

Because we are the first generation born here we are brought up with guilt, I call it the Catholic guilt … like my mum says 'go on holiday' and I can't … I don't want to leave that responsibility so that guilt chips away at you. It's not because they [our parents] are forbidding you or stopping you, but you know that they are 86, 87 when that phone call comes, it is going to happen, because they are elderly. … we didn't see old people when I was young. I went on holiday in 1975 to Rome with J's mum and dad [a friend] and a whole group of other people who I thought were old people; they were younger than I am now.

> (Hungarian female carer, 52, living alone)

Their identity as Muslims formed a strong element of all Pakistani and Bangladeshi participants' narratives. In their words it was very important to acknowledge the practices and behaviours related to their religion for effective and lasting communication with older people of Muslim faith.

Self-reported care and support needs

Trust

Many older people and their carers highlighted the need to establish trust between care staff and older people through effective and continuous communication. A high level of concern was expressed about safety at home, particularly in relation to scams and theft.

I want to know a person before I let them in, I mean they need to sign something because so many people they could … take money out because [if they make you] sign something … I mean it's harder to trust people.
(Italian woman, 68, living alone)

However, the study participants did not just talk about trust when referring to their personal safety when having 'strangers' visiting them. Older people, above all, referred to their need of having confidence in their care staff before they could give them those tasks that they could no longer do themselves, but which they felt were important to their well-being and quality of life.

When a person has been house-proud all their life and they sit there and they're looking round their home and they're thinking 'oh that wants doing', if they can't get jobs done that they used to do, that could do more damage to their health than anything else.
(White British woman, 82, former home carer)

In this case, trust was important because often older people evaluated the quality and standard of the help they received from others against what they themselves used to do. The following extracts from the focus group with older Italians exemplify the importance of trust in the relationship with care staff.

This lady who I go to see she is 88, I do her shopping. She wasn't happy with how things were going with her previous helpers, she was paying at lot of money, they tried to trick her. She said to me 'I was watching you and I was telling you certain things on purpose to see how you answered'. When she saw that I was buying what she wanted … Marks & Spencer, it was

from the receipt she knows if I have been there or not and I have brought her the right change.
(Italian woman, 74, living with husband)

Trust was also central for carers. Carers talked about the need for trust mainly with regard to the choice of giving over to others those tasks they needed help with. They often made clear that they did not intend to have help delivered at any lower standard than that to which they, as family carers, performed.

Some people think that we can't expect professional carers to look after our children like we do. I say, course they can look after my child like I do! They can't love him like I do, but they can look after him like I do! That's nonsense. They think we are handicapped at times.
(White British woman, 73, living with husband and adult son with learning difficulties)

My mum had care workers coming three times a day and you would have thought that in that time when they are in the house you can nip out, have a cigarette, run to the shop, have a cup of tea, but you can't do that, because there wasn't that level of care….
(British Black Caribbean carer, 46)

Trust took time to develop but the presence of some form of previous connection between the older person and care staff facilitated the development of trust. Older participants and carers from minority ethnic groups stressed that these connections did not necessarily imply a common ethnic background between care staff and the older person. A strong feeling of trust could be more promptly developed with any care staff who, at any point before the caring relationship, had shared some social networks with either the older person or their carer. This point is exemplified in the view of a 46-year-old male carer of Caribbean background:

There was a black carer who came here and she realised that I was good friends with her brother and that level of trust actually built, I was reliant on her, mum developed a relationship and loved it. Then there was a white carer who came in and

I actually went to school with her and she was now caring and it was a case of well I know you from school and mum developed really good relationships with them....
(British Black Caribbean carer, 46)

Relief from loneliness
A small number of study participants in the focus groups with older people of Italian, Polish and Ukrainian background, and in the focus group and individual interviews with Pakistani and Polish female carers, talked about their experiences of loneliness. Loneliness was generally described as spending long periods of time in solitude without talking or having meaningful social interaction with anyone. It often seemed to be the final outcome of a process of loss, one after the other, of valued companions until the point in which no companionship was perceived as available. Missing contacts with close family members, for example, partners, son and daughters, was frequently the first element in the study participants' descriptions of loneliness. Older people of minority ethnic background often described the unavailability of members of their own community of origin with whom to interact socially as a significant loss.

We all live very far apart from each other to give help [referring to family members]. Where I live I have nobody, nobody Ukrainian to go to. So I don't have anything to do with anybody and your neighbours every time they don't have time to say hello. Once you shut that door, you can be in that house for days and days with no one to speak to.
(Ukrainian woman, 75, living alone)

The psychological effects of loneliness were aggravated by health problems that reduced older people's capability to engage in social activities and to interact with others.

I don't know, I just give up. Both my sons are living overseas and my husband died, so I have nobody here. I am alone. I am not capable to do any crafts or any bingo and when the other ladies do the bingo I can't do it. I just sit and watch and that breaks my heart. I can't walk, I've got arthritis, I walk slowly. This

is not a life and I've got nobody to turn to. I know one lady but she's got somebody else to look after her.... It's very lonely to live by yourself. I've got no family and it's very lonely.
(Polish woman, 73, living alone)

When asked what could help to relieve loneliness, the study participants often suggested that visits to day centres or community centres in some cases can help to ease older people's loneliness.

The day centre where my husband goes all day Monday, Thursday and Friday morning. Today they are out for the day trip. That is the best thing [speaking of how to ease loneliness].
(White British woman, 83, living with visually impaired husband)

They know a woman who now attends the centre and who they knew was used to spend long periods of time alone, feeling lonely. So, they invited her to come to the centre and spend time with them [referring to a group of women attending focus group]. So she started to come and she felt a lot better.
(Focus group with Bangladeshi older women, through interpreter)

Informational needs

Most study participants mentioned that there was a lack of or insufficient information about the availability or function of formal services. Lack of information generated a range of emotional responses, from frustration, anger and disillusion to hope that things could be improved. Two experiences concerning knowledge of services were consistently reported:

- not receiving, usually for significant periods of time, services or benefits to which they were entitled; this often happened because of a lack of knowledge about the relevant services/benefits at the time when they first became entitled to them;

- not being aware of whether services existed that could help them satisfy their current needs of care and support.

Services and benefits that participants had missed out on included:

- universal benefits, such as free television licence;

- specific benefits and services, such as Carer's Allowance and the provision of medical devices or adaptations for the home.

A 61-year-old woman reported that after she had spent two years checking her mother-in-law's tablet intake on a daily basis because she tended to overdose, the doctor finally gave her a tablet dispenser.

Three common elements were found to affect the ability of the study participants to access information concerning service entitlements:

- a health problem that resulted in admission to hospital. Older participants often reported having been contacted by service providers after their hospitalisation;

- a relationship with people who worked for service providers;

- attendance at recreational or community centres where information and support concerning service provision were provided.

There was a considerable preference for accessing health and informational services locally. Participants suggested that it would be useful to have an officer from the adult services department for a few hours every week at their GP practice to answer questions about older people's entitlements, as it was the most accessible place for them. This would meet two needs:

- a practical need, as local services are more accessible (older participants had restricted mobility);

- an emotional need, as local services build on trust within communities and neighbourhoods.

Many older people said that they had slowed down in terms of how quickly they were able to process large amounts of complex information. Some study participants said that they found it difficult to follow several options of telephone voice message menus that many service providers have. They also found it irritating to be kept on hold on the telephone for prolonged periods of time, as this affected their telephone bills. They often mentioned that they would prefer to be able to leave a voice message and to be called back by a telephone operator.

The need for increased time to process information also had a major impact on face-to-face interactions such as assessments. In the focus group with Polish carers, it was suggested that social workers should allow more time for older people to process the information and to share it with their next of kin.

Older people are often misunderstood. After professional carers visited my parents they said to me 'Oh we have had a word with them and they agreed to this and agreed to that….' and I am thinking, mum and dad have agreed to that? … So I would talk to them and they would say 'I have never said that'. Professional carers ask them 'Do you understand?' [in a slow speech], and they keep saying, 'yes', and then the minute they have gone mum says in Polish 'I don't want to see them again' [laughing].
(Polish carer, 56, living with husband)

When professional carers say to older people, regardless of what nationality they are, 'Do you understand?' I think they should err on the side of caution, because older people can have dementia or a bit of Alzheimer's and when they say 'yes' today, tomorrow it means 'no' … I object to social workers talking to my mum when I am not present, because I know that my mother would say things to please them, but she is not telling them the truth.
(Polish carer, 54, living with husband and mother)

The timing of information provision was important. Often older people were offered information about service provision immediately after a health crisis. In some cases, participants did not take up services at that time in the conviction that they could manage the caring tasks on their own, without

any external help. However, after a few months, they often found themselves struggling. In these cases, older people often did not contact the adult services department to revise their situation, neither were they offered further help (see section on accessibility of services in Chapter 5).

Translational needs

In some communities it seemed that language skills among older people were linked to gender, although the pattern was not consistent across communities. For example, one female carer of Ukrainian background said that in her experience older women had better English language skills compared to older men. This was because women, when younger, had more opportunities than men to communicate in English: while doing their shopping or while socialising with other parents. The men had mainly worked in textile factories, characteristically very noisy work environments, where communication between workers was difficult. They socialised predominantly at the Ukrainian club, where they spoke Ukrainian. Therefore, the men had fewer opportunities to communicate in English compared to the women. This affected their language skills and, eventually, in old age, their communication abilities.

In the Bangladeshi and Pakistani communities it would seem that the women had often weaker language skills compared to the men. Our analysis of the narratives of Bangladeshi women identified three main reasons for this:

- Women's roles were confined to home-making and attending to domestic affairs because they came from a traditional patriarchal society.

- Women experienced a high level of isolation after their arrival in the UK. Often they did not have any family members or acquaintances in Bradford, apart from, occasionally, some relatives on the husband's side.

- It was the husbands who interacted with service providers and translated for their wives.

The combination of these factors significantly restricted Pakistani and Bangladeshi women's opportunities to gain English language skills.

The socioeconomic status of older people from minority ethnic groups was an important factor associated with language needs. In the focus group with Ukrainian carers, the study participants pointed out that often their parents' knowledge of Ukrainian was not very sophisticated because most of them had had a low education.

See we never knew, my parents and nobody I have ever known knew the word 'toes' [in Ukrainian], they have always been thick fingers on your feet, it's always been like that … that is the language they speak. Now, the correct word is an old Ukrainian word … which means toes, but nobody here uses that language. People were looking through the leaflet about diabetes and caring for feet saying, what is that word? A lot of them came from basic places, villages, they couldn't afford higher education and all of a sudden there is this word, 'what are they talking about?'. Eventually we got the English version of the leaflet and went through it and found out that that word meant toes.
(Ukrainian female carer, 52, living with husband)

It should be remembered that the participants who took part in this study did not constitute a representative sample of Bangladeshi, Pakistani and Ukrainian older people in the UK. However, regarding English language proficiency, in the Fourth National Survey of Ethnic Minorities, Modood (1997, p 60) reported that in a nationally representative sample of 5,196 people of Caribbean and Asian origin, 'considerably fewer Pakistani and Bangladeshi women (54 and 40 per cent respectively) spoke English well'. The proportion of men who were judged by the interviewers to speak English fluently was more than three-quarters in both Asian groups.

Summary

- Older-older participants and older participants with health problems experienced increasing difficulties in performing household tasks that required strength and agility.

- Family carers wished for more coordination among different care providers to reduce pressure and constant sense of responsibility.

- There was a strong preference for accessing health and informational services locally.

- Isolated older people were seen as a highly vulnerable group in case of a health crisis.

- Communication, understanding and trust were considered important to the establishment of an effective and lasting relationship between carer staff and older people.

- In older people's and carers' narratives, trust formed the basis for their decisions about handing over those tasks that they could not do any longer by themselves and for which they needed help.

- Loneliness directly affected a minority of participants.

- There was a lack of information about the availability and function of formal services.

- Language skills seemed to be linked to gender in some communities, although the pattern was not consistent across ethnic communities.

4 Experiences and expectations of support from family, friends and neighbours

In this chapter we discuss the findings concerning the commonalities and differences in older people's experiences and expectations of support from family, friends and neighbours.

Support from family

The experiences of support from family members varied significantly between the White British study participants and first-generation minority ethnic older people. The main cause of this difference seemed to be the impact that the immigration process had had on the lives of the respondents from minority ethnic communities. In the majority of cases, the participants from minority ethnic groups had no family members in the UK at the time of their arrival. This was the case particularly among White European older people. Some older African Caribbean, Bangladeshi and Pakistani women referred to one or two relatives already in Bradford at the time of their arrival. Usually these were the husband's male relatives. Consequently, for many years after their arrival, partners were the only source of family support available to the majority of these women.

These participants' experiences of support from family members changed as they grew older, because they created their own families. The majority of the study participants were in contact with their children at the time of the interview. The intensity of their contacts was mainly affected by two factors:

- the physical distance between their places of residence;

- how busy their adult children were because of their work and family commitments.

Some older Bangladeshi, Indian and Pakistani couples lived in multigenerational households together with the family of one of their children. A small number of much older, widowed White and African Caribbean women lived with their adult children. The majority of the respondents lived independently. Older participants often pointed out how busy their children were and how difficult it was to receive help from them when they needed it. This question was raised particularly when they discussed forms of instrumental support, such as help with carrying out household tasks or home repairs.

The level of older people's dependency on help and support from their children was affected by two main factors:

- their state of health;

- their fluency in English.

The majority of the Bangladeshi respondents and some older Pakistani men fully relied on their children to obtain doctors' appointments or to contact service providers, as they could not communicate in English.

Often minority ethnic study participants provided views on their culture of origin when they spoke about their expectations of care and support. These views emphasised a number of character traits deemed to be typical of each specific culture:

- Hungarians, Poles and Ukrainians tended to describe themselves as hard working and proud people.

- Italians tended to describe themselves as hard working and family oriented people.

- Irish people tended to describe themselves as a cohesive community.

- Bangladeshis, Indians and Pakistanis tended to describe themselves as family oriented and caring people, although some study participants proudly talked about their careers.

- African Caribbean participants tended to describe themselves as hard working and family and community oriented people.

White British participants also expressed views on themselves as a people. However, these were related to their social status or their neighbourhood of residence. These views on one's culture or social group of identification were used as important explaining factors with regard to:

- the commitment that could be expected by 'others' to providing care to family members and older people. Study participants of minority ethnic background, with the exception of Irish participants, usually perceived English people as less prone to care for their older people.

- why older people seek or do not seek help when they need it. For example, Hungarians, Poles and Ukrainians suggested that their elders may not look for help when they need it because they are 'proud people'.

However, overall, in every group, most participants agreed that there were family members who were committed to caring for their ageing relatives and others who were not.

There was a common view that it was unrealistic to expect adult children to move in with their ageing parents because they had their own lives to live. However, depending on their ethnic background there was a difference in older people's expectations about whether their children should provide help and support in general. In addition, these expectations were intrinsically linked to gender in some of the minority ethnic groups. A small number of older White British women felt that adult children should not be expected to provide full-time care for their parents or siblings. In the interviews with Bangladeshi, Indian and Pakistani

older people and carers the participants explained that sons traditionally had the responsibility of looking after old parents, because sons kept their ties with their family of origin after marriage, whereas daughters, once married, were expected to dedicate themselves to the care of their new family. The White British, Irish, White European and African Caribbean participants did not express traditional expectations about who among the children should look after ageing parents. However, in most cases, daughters were indicated as the best candidates for taking care of them.

A few participants across ethnic groups mentioned difficult relationships with adult children. Some older Pakistani women living in multigenerational households reported longstanding conflicts with their daughters-in-law and expressed the wish to live independently. However, financial constraints and ineligibility for public housing benefits restricted this possibility. These cohabitations were a major source of stress and clearly affected their well-being. Overall, there was an emphasis on older women being able to make independent decisions about their own living arrangements.

Some of the participants were full-time carers of young adults with learning difficulties and described numerous short- and long-term challenges.

As ageing parents, they were often in need of help for themselves. Nevertheless, they were the main source of care and support for their adult children, who had a variety of needs and different capabilities to live independently. Some could not be left alone at any time, because they could be a risk to themselves. This had a major impact on the parents' ability to socialise. Although in some cases the children were physically able, they were unable to help around the house because of their learning difficulties.

> I would be fine if my son could help me at home, but he doesn't. There are a lot of things that he could physically do for me, but he is frightened of doing them.
>> (White British woman, 75, living with husband and adult son with learning difficulties)

This group of older carers was characterised by two main worries. One worry was that if they became

unwell, they knew their children would not be able to call for help. They were not aware of any service that could help them in such circumstances. The other worry concerned what would happen to their children when they would not be any longer able to care for them. This thought was a source of major anxiety.

Support from friends and neighbours

Friends and neighbours had a significant role in providing instrumental, emotional and informational help across the lifespan for all the study participants. Friends were particularly important as a source of instrumental and emotional support for those who had migrated to the UK. Hungarian and Polish participants, in particular, described how friends often had prominent roles as sources of support both before and after their arrival in the UK. Often friends were the only companions with whom the entire process of migration could be shared with, from the planning to the actual journey and through the various stages after their arrival. However, only a small number of participants reported having maintained the same friends through the stages of migration, because in the early stages of settling in the UK they tended to move frequently from one city to another, looking for better employment opportunities. This was particularly the case with regards to the Hungarian migrants. Regardless of the length of the relationships, the friendships were always described as deep, empathetic and a fundamental source of emotional support.

All the participants referred to neighbours as a good source of help and support in their everyday life. They stressed that neighbourly support networks were still present in some form despite the major and ongoing changes in residency experienced in some neighbourhoods.

Where we live now is virtually, it's total Asia, they are all Asian, but now we have the Slovakians, we have got Polish every nationality in the area that we live.… But even as they have moved in, as people have moved in if they have wanted jobs doing, they have found out and come knocking as I still get some Polish some Russian

from everybody, they still come to my door [and ask for help with their masonry jobs].
(British Irish man, 59, living with partner)

When Bangladeshi and Pakistani older women talked about their arrival in the UK, they mentioned neighbours rather than friends as a primary source of help and support. Older Hungarian, Italian, Polish and Ukrainian participants and carers reported providing or receiving help with errands or regular household chores for payment from some closer neighbours. Financial restrictions were a double source of concern for this group as the restrictions limited their capability to access private forms of support as well as informal, neighbourhood-based help.

Although the vast majority of participants felt that they could rely on their neighbours for some help, they also felt that there was a limit to the commitment that could be expected of neighbours. For example, neighbours could not be expected to be an informal source of full-time care and support.

For African Caribbean participants, experiences of racism had been common in their first years in the UK in the fifties and early sixties. Many examples were given, such as not being allowed to go inside certain shops, as they had signs saying 'for Europeans only' or 'no blacks or coloured', and having difficulties finding lodgings because English and Polish landlords refused to let rooms to black people. In addition, not being able to apply for jobs they were qualified to do because some jobs, for example white-collar jobs, were not offered to black people, was a major frustration. This led to the development of solidarity between some groups of minority ethnic groups. As an example, Pakistani owners of lodging houses were prepared to give hospitality to African Caribbean immigrants when they first arrived in Bradford. Interestingly, none of the participants referred to racist episodes in their stories about their current life experiences.

Summary

- Partners were the only source of family support available to the majority of minority ethnic participants for years after their arrival in the UK.

- Older Bangladeshi, Indian and Pakistani participants who lived together with their adult children stressed how busy their children were and how difficult it was at times to receive help from them.

- Some older Pakistani women wished to be able to leave highly stressful cohabitations with their daughters-in-law and live independently.

- A number of older study participants of Bangladeshi and Pakistani background fully relied on their children to contact any service providers, as they could not communicate in English.

- Traditionally, sons in the Bangladeshi, Indian and Pakistani communities had the responsibility of looking after old parents.

- White British, Irish, White European and African Caribbean older people did not express traditional expectations about who among the children should look after ageing parents. However, daughters were usually indicated as the best candidates.

- Neighbours were considered as a good source of help in everyday life. However, they were not expected to be an unpaid source of full-time care and support.

- Dynamics of solidarity between some minority ethnic groups developed in certain times of need, for example between the African Caribbean and the Pakistani communities.

5 Experiences and expectations of support from health and social welfare services

In this chapter we focus on older people's and carers' experiences of and aspirations for services. The word 'services' is used broadly, including not only health and home care, but also transport and housing. Participants' expectations about services are described under three headings:

- 'Eligibility' refers to the participants' expectations regarding their entitlements as well as the circumstances that made them ineligible for service provision.

- 'Expectations of good practice' and 'not worth the money' refer to experiences and factors that affected the participants' evaluation of services.

- 'Accessibility' refers to the issues that prevented study participants from accessing services.

A particular emphasis is placed on the specific differences and similarities across the various ethnic groups concerning accessibility and acceptability of services.

Eligibility

Several study participants had been excluded from the provision of services through means testing. Among those who were entitled to receive services, there was disappointment if they had to pay some contributions towards them. There was an expectation that as they paid taxes during their working life, they should now be entitled to receive help free of charge. This view was particularly prominent among older people from minority ethnic communities.

> *He worked for 40 years, now because he has retired, financially he is in a lot of trouble,*

and again he feels that he has given a lot of his time and effort working in this country, he paid his taxes. The government was saying pay taxes, pay this, pay that, we will look after you in your old age; now that he is old no one wants to look after him.
>
> (Bangladeshi man, 78, living with extended family, through interpreter)

> *It's a problem.… They don't take into account that you've worked for years and years and that you've paid for all the taxes, that you've worked in factories. If anything happens to you and you can't move or you've got a problem they don't look at the patient, they look at how much money you've got to see whether you have to pay or not.*
>
> (Italian man, 81, living with wife)

There was concern about the financial burden associated with regular payments for service provision. Many were barely above the financial thresholds for eligibility to services free of charge. Consequently, having to pay for service provision impacted on their financial situation. There was an unwillingness to draw from their savings to pay for services that they would not be able to afford on their regular income otherwise. This unwillingness was motivated by the strong desire to be able to leave a lifetime of savings to their families. These savings were often accrued through many tribulations and doing without, and the prospect of having to spend them just to be able to cope with the difficulties of old age was strongly resented.

> *She physically can't go very well. She needs two people to help her down the stairs. I asked the social services if they can help towards it, and they said, no because [you have savings].*

She would like to leave [some money] for her son and the great-grandchildren, but now she's not in a position to do that anymore, because she is forced to spend her own money to sustain her in her old age life. It's very, very sad, when she worked all her life and looked after the children, everything, and now everything will be taken away from her.

(Hungarian older man, 70, caring for English partner)

Older people of Bangladeshi background spoke extensively of the financial difficulties that they faced after their retirement. One of them remarked that these affected his family's health as they often had to decide whether to buy food or save money for their bills:

His house is in disrepair, the council isn't helping with regard to providing a grant for the repairs; he's caught in a catch-22, because the house is draughty, cold, he has to heat the house, to heat the house he has to choose between food and paying the bills.

(Bangladeshi man, 74, living with wife, through interpreter)

Some of the Bangladeshi participants reported that they were unable to obtain grants for basic house repairs.

He has applied twice for grants, but they wouldn't give it to him. When he applies people come, knock on the wall and say that the wall is hanging off, so everything is fine. They say that they'll change the lock and they'll change the insulation in the roof, and that's it.… The council says financially they are unable to afford to give the grant and that is the answer he gets every time.

(Bangladeshi man, 75, living with wife, through interpreter)

Carer's Allowance was often an object of controversial opinions among carers. Whereas some were grateful for receiving it, others were disappointed because they were not entitled to it even though they were providing full-time care to a dependant. Particularly, there was a perception

among some of the participants that older full-time carers were not entitled to receive Carer's Allowance if they received a retirement pension. This was frequently a source of frustration among those who had stopped receiving it after their retirement. They thought that this was because retirement pensions were considered a benefit and that two benefits could not be claimed at the same time. Participants resented this, as they felt that they had paid for their retirement pension through their work and did not perceive it as a benefit.

I can't get Carer's Allowance because I have got my pension, they say I can't claim two benefits at once, like I said the pension isn't a benefit, I have paid my pension, I have paid for it. So you see once you are sixty you are doing the same job [caring] you were always doing, but you can't have anything for it.

(White British woman, 60, living with disabled husband)

Home care

Most of the participants would have liked to receive some help at home with their household chores. However, those who had asked adult services for help with tasks such as cleaning and cooking had been informed that such services were not provided.

Some of the Pakistani participants said that they had been told that they were not eligible to receive home care services because they had a supportive family. This meant that the family carers did not receive any support to carry out their caring duties.

There was a general perception that home care and social services did not provide the same help that they used to give in the past:

Social services do far less than they did twenty years ago. They would clean houses, they would do washing, they will not do this kind of jobs now. They help people get up from a chair, not lift them, because of health and safety.

(Polish female carer, 54, living with husband and disabled mother)

I used to do the windows and change the curtains and everything, but they can't

do that today. They do nothing today, not
like we did, it's not the same service.
    (White British woman, 82, former care staff)

Some study participants had received 'meals on wheels' at some stage. Among these, some said that they received a weekly delivery of frozen trays of food that they had to store in their freezer and heat up in their microwave when needed; some said that they received hot meals. None of the study participants was receiving meals on wheels at the time of the interview. The participants who received frozen food, generally expressed a preference for freshly cooked food. However, some of them disliked the idea of eating frozen food and had stopped the service. These study participants did not seem to be aware of the possibility that they could have food delivered hot, rather than frozen. Older study participants of minority ethnic background expressed a preference for a diet based on their own national dishes. Those of European minority backgrounds pointed out that although the meals on wheels service offered a choice of Asian dishes and halal food, it did not offer specific dishes from different European countries. However, all study participants, irrespective of their ethnic background, emphasised that the provision of food in residential settings or through delivery services, such as meals on wheels, should aim not only to provide a variety of dishes that could cater for different ethnic communities, but also to consider quality in the preparation and attention to individual preferences. Most study participants who had tried meals on wheels did not rate the taste of the food very highly. It was often suggested that local community centres that already offer some catering services for their communities could be involved in the preparation and delivery of food for meals on wheels. Barriers to the formal involvement of community centres in the preparation of meals, such as for example hygiene, health and safety and financial issues, were often acknowledged and discussed by the study participants.

If we are going to do a 'Polish meals on
wheels', the person who cooks has to have
the basic hygiene … if you are cooking
at home you can do whatever you want,

but once you do it for others out there
they want to check the certificate.…
    (Polish carer, 56, living with husband.
    Focus group interview)

They [the social services department] have
got to give some grants … I mean if people
are coming to the centre, they would like
them [the social services department] to
pay the money here for any service, for food
or anything that they're getting through the
centre. So they [the social services department]
must pay here to get that.… If they gave the
funds, they may want to see how it is spent,
well that is a different thing, but they just say
no.… Whichever department you go to they
are thinking of how to save money, how to
economise, so that's the thinking now.
    (Pakistani man, 68, living with wife and adult
    children. Focus group interview)

Housing

The majority of the participants lived in private properties. Only a minority of the participants lived in sheltered housing and none in residential homes at the time of the interview. However, some had stayed in care homes for a few weeks each year to give respite to their carers. A few carers in the interviews had experiences of dealing with care homes.

Some of the participants who lived in terraced or semi-detached houses talked about increasing difficulties living in their current accommodation due to health problems that made it difficult for them to climb stairs and clean. In these cases, the option of moving into more suitable accommodation, for example a bungalow, flat or adapted housing, was considered either autonomously or following a suggestion by health or adult services officers. Some participants had planned to move into one-level accommodation before health problems set in, as part of their retirement. Others had been able to arrange to move into a new house soon after they had had a health crisis that made it too difficult for them to continue living in their old home

I wasn't well really, I got the flat because it
was difficult with the stairs in a big three-story

house, I haven't sold it yet because I can't in this moment in time with it being crap.

(British Irish man, 67, living with wife)

However, the option of moving into more suitable accommodation was not always the preferred choice. Three main reasons were given: financial concerns about buying and selling property; fear of moving from a familiar environment to an unfamiliar neighbourhood away from friends; and concern about their future health.

Oh yes they went through that, going to invalidity housing where they will rehouse you, but you never knew where you were going to go or when this would happen.… Where we are now here it's quiet. I was frightened, they may rehouse us to the middle of an estate and I could have been hounded by hooligans, you don't know. I mean it's alright they make them especially for older people, but the wrong element is that everybody is disabled and make a B-line for them, I didn't want that. If anything happened to Steve, I can have that [pointing at the stairlift] taken out and be back to normal. I don't think it would happen to me and not him. All I worry about is if anything happens to me, what will happen to him?

(White British carer, 62, living with disabled husband)

The decision to move was therefore based on a range of complex considerations of available options. The carer was frequently involved in the final decision.

Transport services

Only a minority of the participants had access to a private car and were able to drive. The majority either walked or used public transport to move around. Many relied on their children for private transport. Private transport was mainly used to do major shopping or to go for doctors' or hospital appointments.

A group of Pakistani participants who had problems walking long distances, who said they did not qualify for mobility benefits, reported growing difficulties getting to places. Shortage of car parking spaces in the town centre, where they

had most of their interests and social life, meant that they often had to leave the car far from their final destination and then walk. This was a source of frustration and physical strain.

It's difficult for me to go to the town, because I can't walk long because of my legs. And there's no parking in places, mostly you cannot find parking. I applied for that badge, but they said unless you are getting Incapacity Benefit you can't have it.… So that actually means that we are deterred walking out and going out. So we come together here [to the community centre] and sit and talk.

(Pakistani man, 78, living with wife)

They were also under the impression that they were not able to benefit from the 'access bus' service, because they did not receive Mobility Benefit.

Health services

Contact with health services was mostly described as experiences of general practitioners (GPs), experiences of local hospitals and experiences of ambulance services.

Descriptions of participants' experiences with GP practices ranged from very positive to quite negative. Positive opinions referred to two factors:

- the ability of GP practices to arrange doctors' appointments for older people quickly, within a day, and not after a week;

- doctors who showed a genuine interest in older people's individual cases.

Dissatisfaction with GP services related to:

- lengthy waiting times for appointments;

- ageist attitudes; being stereotyped as 'old', and therefore not receiving sufficient feedback or attention to their health problems because the problem was attributed to old age.

GPs just think that we are getting old, so things are bound to happen. That is all they say. You know what the doctor says to me most of the time? Oh, you are too heavy, you should

diet [laughing]. I have been this physique since 1930, since my age 30 or 34. So 'you should lose your weight' and if you are too slim 'gain some weight', one or the other.

(Indian man, 80, living with wife)

In a number of cases, participants pointed out deterioration in the level of care and support they received from the nursing staff in hospital:

About three months ago he stayed a month in hospital. The trolley person who brought the food dropped it in front of his bed, and left. If you want to eat, you eat, if you don't want to eat, don't eat. The time comes for them to come and collect it.… There is no one who feeds, not like they did before. Before the nurses used to come and ask: 'Are you eating?'. Now they don't bother. So, the care and attention that used to be given before has gone away.

(Bangladeshi man, 68, living alone)

Participants also described experiences of poor coordination between different service providers. These experiences were a source of major frustration and disappointment. One White British carer, for example, stated that in her experience members of staff of different health services departments 'never check their notes'. She talked about a number of frustrating episodes in which service providers failed to meet her needs, for example:

My husband was admitted to hospital [he is disabled] … but nobody reads the notes … the ambulance man is pushing him into the [hospital] and he shouts to the sister 'Oh! I have got a patient for you'. She shouts back 'Oh no, I am only expecting one today. It's a walking wounded'. So I said 'Excuse me, who is that one you are expecting? Is it […]?'. 'Yes'. I said 'He isn't walking wounded, he is here, he is disabled!'. She had put him in a ward on his own that was miles away from a toilet because she hadn't read his notes.

And:

One day I had three ambulances outside my house because they sent an ambulance with one man driving, it had a portable lift … but he was only one man and he wouldn't take him. The second ambulance came, there were two ambulance people, but no lift, so they wouldn't take him, three ambulances turned up knowing that he had an appointment to get to.

(White British carer, 62, living with disabled husband)

This lack of coordination between services also became apparent in examples of older people who lived alone being discharged from hospital late at night without backup support. This caused unnecessary anxiety and participants felt that there was a [hidden] expectation that family and neighbours should take on the caring responsibilities for the older person who was discharged, without being consulted about it.

Similarly, in the focus group with older parents of adults with learning difficulties, a number of episodes were reported in which main carers had been taken to hospital by ambulance and their adult children with learning difficulties, unable to live independently, were left alone at home. The study participants pointed out that there was no protocol that took care of adults with learning difficulties in case of an emergency with their main carer.

Some study participants reported long waiting times for an ambulance to arrive.

Last Tuesday I rang for the ambulance at twenty to seven and they told me I must do 999 and get one sent as soon as possible, it was twenty to eleven at night before one came.

(White British carer, 59, living with disabled husband)

Expectations of good practice

Participants expressed strong views about what constituted 'good practice' in the way services were delivered. This expectation was related to the needs of trust, understanding and communication discussed previously and had a major impact on decisions about retaining services or not. The notion of 'good practice' was associated with perceptions of professional and ethical standards

in the delivery of services. Examples of perceived poor professional and ethical practices included:

- care staff not washing their hands on arrival, for each new client;

- using the same cloth to wash the face as well as the rest of the body of the older person;

- not following basic hygiene practices such as cleaning the bowl used to wash the older person and re-using it dirty the following day;

- not tidying up after completion of care tasks;

- not respecting the dignity of the individual.

Some examples of failure to meet the expectations of good practice were strongly related to questions of ethical standards in service provision:

He is giving you an example of a lady who became paralysed, she could eat a little bit through the mouth, but she couldn't pick it up and eat it herself.… She had children, but they were advised that a residential home would be the best place for her, because of the commitments of the children and everybody else. So they took her to a residential home … the workers there said it took too much time to feed her because she was slow, so they started feeding her intravenously. Then the family started saying what's the point of this; my mother can eat through the mouth, it just takes a little bit longer to feed her, she would get worse! So they got her out and the family have taken over the role, and they feed her and look after her.… So basically there was a disillusion with the service they were getting.
(Bangladeshi man, 68, living alone, through interpreter)

Some other examples seemed to be more related to lack of professional standards and lack of training of the care staff.

There was two [care staff] who were coming for seven a.m., that was good.… However, you could always tell if someone new had come

because the towel would be left over the settee and the top half of his pyjama and vest would be somewhere else, they were never all together neatly. Yet, I left everything out neatly for them, the clean clothes for him to put on and his toothpaste and everything there for them.
(White British woman, 62, living with husband)

Even though I would meet with the care manager and I said this is what is done, I would never catch water in a dirty bowl and bring it in front of the person you are serving and then proceed to wash them.… In the end as mum has got stronger she has started to help herself, but she wouldn't have home care again and I wouldn't encourage my mum to have it.
(British Caribbean female carer, 34, living with family)

As mentioned in Chapter 4, study participants of minority ethnic background often provided views on their culture of origin that were used to explain older people's attitudes towards care and seeking help. However, in the focus group with African Caribbean carers their self-representation of culture was also associated with their expectations of 'good practice' in service delivery.

When my mother had her car accident … we had home care coming, but I had to keep an eye on what homecare were doing; how we care for ourselves is not how the English would take care.…
(British Caribbean female carer, 34, living with family)

I don't know about your experience or dealings with black people, basic hygiene is paramount to us because it is so basic. You don't throw dirty water in the kitchen sink, don't use that cloth to wash her face if you washed her body with it [talking about personal experiences of services received from home care staff].
(British Caribbean male carer, 46)

Religious beliefs, on the other hand, framed many of the Muslim older people's expectations of, for example, halal food and prayer rooms in housing services. However, some older Bangladeshi

women said that they did not expect care staff to replicate all behaviours associated with cultural or religious beliefs, such as feeding with the hand. They simply expected that staff talked to the older people about their wishes, that the tasks were executed properly while at the same time respecting older people's dignity:

She says that they should get good help and a good service, they can't just give them a bath [talking about a previous example].... It has to be not exactly how they want it, but as long as it is decent and they're happy with them and they're not hurting them in any way, then they will actually be satisfied with the service. As long as they do it properly and not just anyhow.
(Bangladeshi woman, 70, living with husband, through interpreter)

Not worth the money

Some older study participants and carers thought that the assistance received from services was unhelpful and therefore not worth the money. This happened when the service did not respond to need and lacked flexibility. Examples of unhelpful or inadequate assistance included:

- home carers putting older people to bed too early;

- social workers helping older people out of bed too late in the morning;

- meals on wheels being delivered at unacceptable hours;

- help provided being minimal or requiring the carer to carry out most of it;

- help being provided through cumbersome and unpractical procedures.

The following extracts from focus group interviews provide two examples of this perception:

I know with Mrs K they used to come at six o'clock to get her ready for bed, her husband wasn't a well man but he'd say she is not

going to bed now, so they would put her in her nightie. I was going home one night and we'd seen him struggling up the stairs to bed with her, I knocked on the door.… Not being funny, but children don't want to go to bed at six o'clock so why because you are older do you need to be put to bed at six o'clock?
(White British woman, 73, living with husband)

Once I asked them to help me because my husband was poorly and I was looking after him.… We are only on a pension, the social worker came and asked me 'have you got savings?'. Then, you have to pay 13.99. I ask, can they do the cooking, cleaning? She said no, they can only give a glass of water and medicines if needed. I said, I can do that job by myself. I can do cleaning, cooking and whole house work and I can do the shopping. Why can't I give a glass of water or some medicine? So I said bugger off, yes I said go, go, go.
(Pakistani woman, 61, living alone)

Accessibility

A number of factors affected participants' accessibility to services. The main factors were as follows.

Availability of neighbourhood based-care staff

Study participants suggested that it would be better if care staff for older people came from their own neighbourhood or community. There was a feeling that it was more likely that a relationship of trust and understanding would quickly develop, as the older person and the professional carer may already know each other or have some common social networks.

Some study participants suggested that it would be good if neighbours and family friends who were prepared to offer care could be acknowledged in the role of formal, paid carers by the relevant institutions. This would enable them to be paid and the older person to receive care from someone they already know and trust. Barriers to involving formally neighbours and friends in the care of older people, such as for example receiving

Criminal Records Bureau (CRB) clearance, were acknowledged and discussed.

Our night workers were ladies from very middle class who where from Ilkley. Suitable people to look after my mum at night actually existed within our own community, maybe a couple of doors away. If neighbours are happy with helping and they're CRB checked and the council passes that check, why can't a local person who knows mum and her needs offer that help? I think it's a case of looking at what is available locally.

(British Caribbean male carer, 46)

If carers live locally perhaps they will know the cared for. What I am trying to say is that if it is someone local to offer care then older people will feel safer, because is not just any stranger who comes from elsewhere, with whom they have no connection.

(Pakistani female carer, 37)

Provision of individualised care

The study participants who talked about their experiences of an assessment by an adult services department often felt that they had not been offered what best suited their needs, but rather what best suited the budget and the protocols of that service. This view seemed largely linked to the belief that there was no flexibility in the way help was offered by adult services. One Caribbean carer explained this by saying that the adult services officers 'don't think outside the box'. Another carer explained it in the following way.

It is like going into a shop to ask 'I want a loaf of white bread', 'sorry you can't have white bread, you can only have brown', 'well I want white bread', 'well you can't, so give me your pound and you can have brown!' and as a consumer you would say 'fine, I will go to the next shop where I will get white bread', not be forced to take brown bread because it is all they have got on offer. But that is what's happening with the services … you have got to pay it and they decide that you have got to have it.

(Polish carer, 56, living with husband)

This lack of flexibility manifested in different ways. Some study participants had offered to pay for some home adaptations, hoping to receive a reimbursement at a later stage, but had been told that this was not possible.

My son cannot get in and out of the bath on his own, so we needed a shower. There was a grant through the local PCT [Primary Care Trust] and I was told 'sorry but there is a two-year waiting list' … I lost my cool with that, I said 'can I pay and get it retrospective?'. I wasn't bothered about that. 'No you can't', what stupidity so ... I had a quote and it's six hundred pounds, well that's what I paid because there is no way that he could physically do anything else. It's hardly decent, if I could physically haul him out of the bath, I did try actually [laughs], I don't know who was wetter, him or me!

(Older White British woman, 75, living with adult son with learning difficulties)

In most cases, the perceived lack of flexibility resulted in the study participants reporting that they did not regard the services that they had been offered as adequate or matching their needs. This was often also caused by a lack of clear communication from the service providers about what exactly they were going to provide.

When my mum first came out [of the hospital] they assessed her. She was wheelchair bound, they said oh don't worry we will get a ramp up. They sent some builders up within three, four weeks of mum coming out of hospital and we had this construction in the back yard. I looked at it and thought, one it's in the back yard, two it looks like you can launch a space rocket off this thing, I don't know … mum was already apprehensive about being in a wheelchair never mind being pushed four foot in the air, totally unacceptable.… So the assessment was done, they ticked their boxes when they provided the ramp, but they didn't mention that it was access to the back.… Well common sense would have told you to have some kind of discussion with the client, that seldom never happens.

(British Caribbean male carer, 46)

In all these cases the study participants were under the impression that the service that they were provided was decided by service providers on the basis of service priorities rather than being tailored to their personal circumstances, needs and preferences.

> *I think it [the service provision] is done on the case of they have got a budget, a client and let's see what we would come up with, some kind of ramp that would come up with three hours and cost a hundred pounds in wood. They [the social services department] would do that rather than looking at a permanent hydraulic lifting that would just fit in perfectly, which may cost three thousand pounds, but would care for that client's needs regarding them being independent.…*
>
> (British Caribbean male carer, 46)

Some older study participants made the point that older people's complex needs require a holistic approach to help with the provision of adequate care and support. This implied that care staff moved beyond the rigid boundaries and procedures of their individual offices and collaborated more closely with each other to meet the needs of older people.

> *It needs someone to link all this together, so that when the person's being discussed it's not just the community nurse that is discussing it, it's her plus a psychologist, plus people that can deal with your disabilities, with your physical things that need doing around the house, a little bit of a team. The money needs to be in at the right place. These organisations are all working separately so you can't do the whole thing.*
>
> (Older White British carer, 77, living with wife)

Often the study participants showed extraordinary resourcefulness in overcoming the lack of flexibility and the lack of information concerning the services provided by adult services.

> *They [the adult services department] tend to think within a box, whereas with my sister, coming in looking at the situation, it's a case of 'what can we do?'. So straight away we got*

shopping online, delivered, she tapped around services other than the council for disabled transport, so we had a transport vehicle with disabled accessibility coming every Sunday to take her to church and bring her back. These were things that we needed to look at ourselves and realise that she actually qualified for them and then tag them on to a package that we created for mum rather than social services. So it was like using them as and when we needed them rather than relying on them.

(British Caribbean male carer, 46)

Carers and older people who relied exclusively on the services provided by adult services, without also referring to complementary ways to satisfy their needs, often had disappointing experiences regarding the lack of individually tailored services. For example, one Pakistani carer reported an episode in which her elderly mother decided to use the 'access bus service' to go to have an eye operation because she was unable to take her there personally. This bus service picks up older people directly from home and takes them to specific destinations at pre-set times of the day. The woman was taken to the hospital in the morning one hour later than the time she had booked the bus for and was only able to return home later in the afternoon, many hours after her eye operation. This was because the access bus went back only after all the people who had used it that day had finished with their appointments at the hospital. This caused major distress for the older woman.

> *My mum was so fed up and she said next time she won't go.*
>
> (Pakistani female carer, 40, living with family)

Perhaps in this case the combination of different transport services such as a taxi and the access bus would have been better.

Older carers with adult children with learning difficulties expressed concerns about the inconsistency of support across different age groups. They pointed out that they received a good level of support when their children were of school age. However, once their children had passed school age, the level of support that they received from service providers dropped significantly.

The lack of flexibility of the services received was again raised as a major issue. However, carers seemed to have different experiences, as the following dialogue illustrates.

I1: *Each one of our children will have a different problem. This is where the system falls down, because well they don't provide their service. But when they did provide the service they provided it for overall.*

I2: *I was going to say that, we are all under one umbrella and it's wrong.*

I1: *Each one of those people that would be sat round a table would be expected to do one thing, whether they are interested in it or not [talking about activities for adults with learning difficulties].*

I3: *Well I have got to speak up here because my son goes to the … behavioural unit and the manager there is absolutely brilliant and he has got a programme for everyone. He has turned the place around completely.*

(White British women, living with children with learning difficulties. Focus group interview)

Timing of information
(See also section on informational needs in Chapter 3.) Barriers to service take-up, such as long waiting lists and lack of or poor communication about entitlements and progress of claims, were a major source of uncertainty and distress. The majority of the study participants who had been offered house alterations or the instalment of house aids, such as ramps or stairlifts, reported that they had had no feedback for months about what was happening with their claims. Because follow-up of the progress of claims was left to individuals' own initiative, people sometimes gave up hope and did not take any action, which resulted in not having any information about the progress of their assessments:

I have had an assessment for a ramp two and three times, but I never follow up and push 'em and push 'em. I have bought a portable ramp to keep putting down myself and they keep telling me I'm on the waiting list. I have been on a waiting list at least eighteen months….

and

We were waiting at least four years before our stairlift was installed.
(White British carer, 62, living with disabled husband)

I1: *I can usually chase things up myself, but I'm chasing that many people….*

I2: *You get to a point where you can't be bothered after a while though and you think nobody is listening.*

I3: *You bash your head up against a wall.*

I1: *But this is the kind of thing that we all struggle with….*

(White British women living with children with learning difficulties. Focus group interview)

Language barriers
See the section on translational needs in Chapter 3.

Lack of acknowledgment of the carer's role and importance
Carers of ageing parents who had young children often expressed frustration regarding the timing of the appointments for hospital and specialist visits of their cared-for, as they overlapped with bringing children to school or picking them up from school.

Summary

- For many participants, buying help through the adult services department was a financial burden.

- For many participants, it was a burden to have to follow up needed services and information and as a result often missed out on services.

- Many participants judged services as unhelpful and therefore not worth the cost.

- Participants resented drawing from their savings to pay for services because they wished to leave their life savings to their families.

- All the Bangladeshi study participants experienced major financial difficulties.

- Study participants preferred care staff for older people to come from their own neighbourhood.

- Participants thought that, in recent years, the quality and extent of available services had become poorer.

- Very long waiting lists to have ramps and stairlifts installed were a common experience among the study participants.

- There was a high expectation that service provision should respect basic professional and ethical standards ('good practice').

- Participants complained that some care staff did not follow basic hygiene practices, such as not using a dirty bowl to take clean water to wash the client or not washing their hands when visiting a new house.

- Communication and understanding of the views and personal caring preferences of older people and their carers were of paramount importance for a satisfactory and lasting caring relationship.

- Older people caring for non-self-sufficient adults with learning difficulties suggested that a protocol was needed to take care of those adults in case their only carer was taken to hospital by ambulance.

- Participants suggested that health and ambulance services should check whether or not older people's support networks (for example, family and neighbours) were available before discharging them from hospital late at night to empty houses.

6 Conclusions

This study set out to explore the needs, experiences and aspirations of care and support among older people and carers from a range of ethnic communities across Bradford. To do this we explored the commonalities and differences in care and support needs across and between ten different ethnic groups of older people and their carers in Bradford, their perceptions of accessibility and acceptability of services and support in relation to information and advocacy needs, and potential for or actual barriers to take-up of services. We also explored ideas for the development of culturally sensitive services and identified gaps in local services for older people and their carers with regards to access, coordination, funding, capacity building and development.

Although this study was first and foremost about older people and their carers in Bradford, many of the issues that were explored will doubtless be relevant to, and of interest in, other parts of the UK. Being a qualitative study, the participants were obviously not a representative sample in a statistical sense. However, we interviewed over 150 individuals who represented a wide range of communities in Bradford, and as such could be said to provide a reasonably accurate picture of older people's experiences, needs and expectations of care and support in those communities.

In this study, older people described needs and expectations that related to their experiences of being 'old', as well as expectations and needs based on their past experiences and their cultural and ethnic identity. These similarities and differences influenced their expectations and perceptions of care and support in terms of both services provided by the statutory sector and the help and support they received from family, friends and neighbours. This was also the case with regards to the views and expectations of family carers. The study illustrates that across all groups there was a desire to be recognised as individuals with their own rich histories and personal expectations and requirements. There

was also a strong perception that older people's personal histories were associated with being part of a particular ethnic or cultural group and that therefore, this ethnic or cultural heritage influenced how they viewed the world around them.

The impact of 'being old'

Many of the needs described by the study participants were cross-cutting, relating to old age and specific life events, such as bereavement or illness, rather than to cultural, religious or ethnic influences. Instrumental support needs, emotional needs and information needs were associated with the types of services older people and carers in our interviews desired. As in a previous Joseph Rowntree Foundation report (Raynes et al., 2006), older people in this study frequently referred to the need for 'that bit of help', such as help with basic household chores or the provision of useful information at the right time. Notably, although the needs were associated with old age, there was an expectation that the service response to these needs should take into account older people's cultural, spiritual, mental and physical health characteristics. Likewise, some of their general experiences of services had more to do with old age and frailty than with their cultural or ethnic background. However, many of these experiences were grounded in the values and beliefs associated with culture and ethnicity and the participants' perceptions of the cultural sensitivity of services, echoing the findings from a number of other studies that have explored older people's experiences of services (Yu, 2000b; Katbamna et al., 2004; Older People's Steering Group, 2004). Yu (2000b), for example, found that Chinese older people could experience double disadvantage by feeling detached from both the mainstream community and their own community.

These interviews suggest that social isolation and loneliness are experiences that are common and similar across cultures. However, there is insufficient evidence to demonstrate whether there

are cultural or ethnic differences in the factors that impact on loneliness or in the interventions that might prevent or alleviate loneliness in later life (Cattan *et al.*, 2005; Victor *et al.*, 2005).

The influence of culture and ethnicity

It was clear from the interviews that older people's personal background and cultural grounding influenced their attitudes and decisions about the care and support they received. As in previous research (Cattan *et al.,* 2003), this study found that many White British older people want to retain their independence and not be a burden to others. On the other hand, several Eastern European carers suggested that the demands for care and support that their parents placed on them were associated with not having the experience of caring for their own parents. For Bangladeshi and Pakistani older people, their religious identity as Muslims was a strong guiding factor in their expectations of care and support. The quality of services, particularly in relation to hygiene, was associated with cultural and ethnic identity among many African Caribbean carers. In their view, poor hygiene practice was related to being White British rather than to substandard professional practice.

In addition to these specific population expectations, the experience of immigration, which all first-generation minority ethnic older people shared, had a major impact on how they approached the demands of old age compared with the White British population. White British older people who had stated that they did not wish to be dependent on 'others' expressed a preference to rely on family for support rather than on external services. Among first-generation migrants, neighbours or friends were frequently their first principal source of help. As they grew older this changed and their families became their first source of help. A small number of older people (mainly Bangladeshi, Indian and Pakistani) lived with their adult children. Their dependency was affected by their level of (ill) health and their English language competency.

Discrimination, ageism and racism

Although the stories of overt racial discrimination referred to the past (for example the experiences of the African Caribbean participants in the 1950s and 1960s), there were also more current examples, which suggest that institutionalised discrimination still exists in services – as has been recorded on numerous occasions (see, for example, Bernard and Scharf, 2007; Cattan, 2009). When care workers repeatedly and slowly ask older [minority ethnic] people 'Do you understand?', this was seen as highly patronising. More significantly, some Pakistani older people felt that they had been considered ineligible for home care services 'because they had a supportive family'. We do not know if the assessments were based on specific assurances that the family would look after the older person, or on a common but misinformed assumption that South Asian families always 'look after their own' (JRF, 2004; Katbamna *et al.*, 2004). So it is difficult to judge whether these examples amounted to racism, or simply to lack of awareness or 'cultural competence'. Older people objected strongly to GPs attributing their health problems simply to their age. In their view, their health problems consequently did not receive sufficient attention and they were in effect blocked from healthcare they were entitled to. Deterioration in hospital nursing care in hospitals and in care homes was described by many. Although these incidences were not directly attributed to age discrimination and ageist attitudes among staff, there is evidence that older people can receive poor care as a result of being old (Ahmed, 2002; Chadha and Young, 2002; Lievesley *et al.*, 2009). Although this research cannot verify these stories, the important factor here is how older people *perceive* they have been treated. Substandard services due to age discrimination have been reported nationally (DH, 2001; Katbamna *et al.*, 2004; SEU, 2006).

Communication, coordination and awareness

There was a general sense of not being listened to or being taken seriously. Some of the stories that could have been interpreted as describing ageist practices may have had more to do with

lack of communication and lack of awareness of older people's expectations. When older people raised the issue of communication, they did not just talk about language barriers and the need for information in their own language. Communication was about care staff being aware of and sensitive to older people's personal desires and preferences associated with their past histories, cultural and religious backgrounds.

The understanding and sensitivity of personal expectations was for many participants more important than having care staff who spoke their language. In their opinion, having an interpreter available was just as acceptable as long as their preferences based on their cultural, religious and ethnic background were considered and acknowledged. Interestingly, many Muslim older people felt that, as long as their desires and expectations, with regards to for example food and eating habits, were discussed and treated with respect, they did not expect care staff to replicate all behaviours relating to their traditional practices. This suggests that the development and application of cultural competency techniques proposed by Brach and Fraser (2000) and discussed in Chapter 2, may be a way for service providers to promote cultural awareness among staff and improve and promote good practice throughout service organisations.

The importance of good communication was also raised with regards to developing trust with care staff; that they could be trusted to do those regular household tasks to the standard expected by the older person. It appeared that older people as well as their carers evaluated the quality of such work on the basis of criteria of 'the way they used to do it' and this of course required that care staff were able to communicate effectively with older people and could understand their expectations. Trust could be strengthened further if the paid carer already had links with the carers' or older people's current or former social networks. This was seen as more valuable than having a common identity through ethnicity.

Effective communication was a prerequisite for information about services and support to be available and accessible. Many older people and carers had at some point missed out on services or benefits as a result of poor communication and lack

of timely information. It seemed that older people and carers perceived the timing of the information communication as critical to the uptake of services and entitlements, an issue that has been raised on numerous occasions in policy documents, such as *Choosing Health* (DH, 2004) and *Our Health, Our Care, Our Say* (DH, 2006). Occasionally, information had been misinterpreted or misunderstood and through lack of communication, not been rectified. Examples of this included not fully knowing what services, such as the 'access bus', they were entitled to use, or not understanding why they were entitled to some benefits but not others. In *Our Health, Our Care, Our Say* (DH, 2006), the government set out to make health and social services responsive to people's aspirations for independence and desires for greater control over their own lives. It would, however, seem that in addition to the difficulties older people and their carers experience in navigating through a complex benefits system, local barriers to this agenda being implemented include lack of information timeliness, lack of follow-up and in some cases lack of sensitivity to older people's individual expectations and desires.

A major source of frustration was the lack of follow-up communication following benefit claims or requests for housing alterations. Some of the interviewees expressed anger at having to wait for several years without knowing anything about the progress of their requests. This problem is not unique to Bradford, but it is an issue that can best be dealt with locally with solutions tailored to the specific circumstances of the local population. Lack of follow-up communication did not just involve waiting for a service. There were examples of alteration requests being agreed and then going ahead without any further consultation, which resulted in a final product that did not meet the older person's expectations. A brief discussion, following the alteration agreement, would more than likely have overcome this problem.

Many participants associated the lack of coordination with poor communication between services. The ambulance services in particular were criticised for lack of coordination with other sections of the health service. Major concerns were raised about inadequate support for older people who were discharged from hospital late at night,

and young adults with learning difficulties being left alone at home when a parent was taken to hospital.

Flexibility and individualisation

Across all groups, a desire for flexible and individually tailored services was evident, thereby supporting the proposals for Individual Budgets taken forward through the government's personalisation agenda (DH, 2006, DH, 2007). However, an evaluation of the Individual Budgets pilot programme found that older people had lower psychological well-being than other groups, possibly due to the anxiety of 'the additional burden' of being responsible for their own budgets (Glendinning *et al.*, 2008). Another explanation may be, as this study found, that older people often require more time to process complex information, potentially leading to anxiety and concern about decisions made during an assessment. An obvious solution to improve satisfaction with individual budgets would therefore be to allow older people more time to absorb and process information relating to their care and, if they wish, to share the information with their family before taking any decisions.

Most older people in our interviews lived independently, with a small number living in multigenerational households. For many South Asian families it was the traditional expectation that sons looked after their ageing parents. This was not necessarily older people's preferred choice. The study found evidence that living in multigenerational families could result in conflict and stress between generations, with little opportunity to change the status quo. Some older women living in multigenerational households expressed a strong desire to live independently, but felt hampered by financial constraints and lack of eligibility for important benefits.

Moving from their family home to more suitable accommodation due to ill health could also be stressful. Older people worried about the cost of moving and about becoming isolated from family, friends and the neighbourhood they were familiar with. There was a general worry about what help would be available for older people who lived alone, with no family nearby, if they became unwell (see also Cattan *et al.*, 2010).

The availability of food and the provision of prepared meals was a major discussion point. On the one hand, there were general expectations about freshness, quality and tastiness of food and, on the other hand, there were individual desires for dishes based on the food they were used to. Although some older people specifically mentioned national dishes, most participants simply wanted variety in their diet and fresh food that met their individual preferences. Interestingly, among those who were eligible for 'meals on wheels', not everyone was aware that they were able to choose between having frozen or hot meals delivered, suggesting that this information was not reaching older people as a result of ineffective communication.

Not worth the money
The lack of flexibility and consideration of individual preferences had frequently resulted in older people and their carers choosing not to have a service because they considered it a waste of money. There were many examples, ranging from help in the home to transport services, where participants felt that the services they were offered were geared towards the budgets and needs of the service providers rather than older people's individual desires and preferences. This was described as services 'ticking the box' rather than listening to older people and their carers. Of course, this is not unique to Bradford and has been recorded in numerous evaluations (JRF, 2004). To some extent, the government's Individual Budgets programme is intended to deal with these problems, but although it covers more than simply social care, there are concerns about the complexity and fairness of resource allocation and the way boundaries for expenditure are established (Glendinning *et al.*, 2008; Manthorpe 2008).

Savings and entitlements

As has already been noted, older people and carers expressed frustration regarding the complexity of access to services and benefits entitlements. In addition, many older people, particularly among minority ethnic groups, were upset at the thought that they would have to contribute financially towards services they were entitled to. There was

a strongly held belief that the taxes they had paid during their working years should now pay for the services they required in old age. Some older people worried about the financial burden of paying for services, while others resented it because they had saved throughout their lives to be able to leave money for their children and grandchildren. Many Bangladeshi older people spoke of financial hardship in their retirement and being unable to obtain certain grants, such as for house repairs. Although the interviews did not unravel why this was the case, other studies have shown that Bangladeshi older people are among the poorest (Chahal and Temple, 2005), live in areas with a high proportion of substandard housing, and have problems accessing services because of poor communication and lack of understanding of their specific requirements and expectations (Merrell *et al.*, 2006).

Carer's Allowance

There were mixed views about Carer's Allowance. It was a welcome support for those who received it, while those receiving retirement pension and who as a result were not eligible for Carer's Allowance could not understand why they could not have both, especially if they had received Carer's Allowance before. In their words, they had been told that they were not entitled to claim two 'benefits', despite arguing that their pension was earned and therefore not a benefit. This perception is hardly surprising as the government's website about Carer's Allowance states: 'If you receive certain *other benefits including the State Pension* which are paid at a rate that is the same or more than Carer's Allowance, you may not receive payment of Carer's Allowance but may have what is called an "underlying entitlement"' (Directgov, 2009, emphasis added). What the 'underlying entitlement' was seemed less clear among those we interviewed.

Resourcefulness

> *… using them as and when we need them rather than relying on them.*

Many study participants displayed an extraordinary resourcefulness in overcoming many of the

problems they faced. In some cases, this resourcefulness amounted to direct action, while in other cases pragmatic suggestions were made about how the services could meet their expectations more directly. In other words, many of the older people and carers we interviewed did not reflect the stereotype of older people being 'vulnerable, passive and done to', but sought individual solutions for individual needs and expectations. Some families had taken direct action and thought about what *they* could do to create a personal care package for their relative rather than simply accept what adult services offered them. In their view, the additional effort involved, provided a service that was right for them. Many of the suggestions involved drawing on local resources, such as community centres providing home meals services and home care being provided by neighbours and people who they knew in their own communities. Potential barriers, such as food hygiene standards for food delivery and police checks for home helpers, while recognised were not considered to be insurmountable.

Key messages

In conclusion, many of the issues that this study identified were not specific to Bradford, but reflected general issues and perspectives of older people and carers across the country. Despite differences in background and cultural experiences, older people and carers in Bradford shared many general expectations about help and support from services. However, many of their individual desires and expectations related to their cultural and religious background as well as to their experiences in childhood and early adulthood. Many felt that their individual needs and expectations were not met because services were run for the convenience of the service providers rather than for the benefit of the service recipients. In addition, there was a strong sense that older people's individual preferences were not acknowledged because of a lack of understanding and sensitivity to the influence of lifetime experiences and cultural background. A major concern was the lack of effective communication between different service providers and between services and older people and carers. The provision of information about

services was often not timely, which in some cases led to older people missing out on much-needed help and support. However, carers' and older people's resourcefulness frequently overcame the problems they were faced with, with many of their solutions based on local skills and resources.

This study has identified a number of key messages for service planners and service providers to consider:

- Older people want to retain their independence for as long as possible and not be a burden to others.

- Older people and carers share common expectations, regardless of their ethnic and cultural background, about the quality and equity of services.

- Older people have individual expectations, aspirations and desires based on their life experiences, cultural, religious and ethnic background.

- The marked differences in lifetime experiences between White British older people and first-generation older migrants have a strong influence on their expectations regarding help and support.

- Carers and older people base their judgement and evaluation of care services on 'the way they would do it themselves'.

- Good communication should develop trust, ensure that information is timely and understood and enable older people and carers to have control over their care packages.

- Older people and carers are concerned about the availability of help for older people, living alone, if they become unwell.

- Older people need more time to process complex information about service entitlements and benefits.

- Many carers and older people miss out on benefits and services they would be entitled to because of the complexity of accessing them.

Older people's and carers' resourcefulness provide solutions that are individually tailored and examples of 'thinking outside the box'.

References

Adamson, J. and Donovan, J. (2005) '"Normal disruption": South Asian and African/Caribbean relatives caring for an older family member in the UK', *Social Science & Medicine*, 60(1), 37–48

Ahmed, K. (2002) 'Elderly suffering ageism in NHS', *The Observer*, 27 January

Ahmed, N. and Jones, I.R. (2008) '"Habitus and bureaucratic routines", cultural and structural factors in the experience of informal care: a qualitative study of Bangladeshi women living in London', *Current Sociology*, 56(1), 57–76

Barrett, J. (2005) 'Support and information needs of older and disabled older people in the UK', *Applied Ergonomics*, 36(2), 177–183

Bernard, M. and Scharf, T. (eds) (2007) *Critical Perspectives on Ageing Societies*. Bristol: The Policy Press

Blakemore, K. (2000) 'Health and social care needs in minority communities: an over-problematised issue?', *Health and Social Care in the Community*, 8(1), 22–30

Boneham, M.A., Williams, K.E., Copeland, J.R.M., McKibbin, P., Wilson, K., Scott, A. *et al.* (1997) 'Elderly people from ethnic minorities in Liverpool: mental illness, unmet need and barriers to service use', *Health and Social Care in the Community*, 5(3), 173–80

Bourdieu, P. (1977) *Outline of a Theory of Practice*. Cambridge: Cambridge University Press

Bourdieu, P. (1990) *The Logic of Practice*. Cambridge: Polity Press

Bowes, A. and MacDonald, C. (2000) 'Support for majority and minority ethnic groups at home: older people's perspectives', *Social Work Research Findings*, vol. 36. Edinburgh: Scottish Executive. Available online at: www.scotland.gov.uk/cru/resfinds/swr36-00.asp

Brach, C. and Fraser, I. (2000) 'Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model', *Medical Care Research and Review*, 57(suppl. 1), pp 181–217

Bradford Metropolitan Council (2003) *First Key Census Statistics for Bradford District*. Bradford: Bradford Info

Bradford Metropolitan Council (2007) *Older People*. Bradford: Bradford City Council

Bradford Metropolitan Council (2008) *The People of Bradford.* Life in the Community. Retrieved from www.bradford.gov.uk/life_in_the_community/population_and_migration/people_of_bradford.htm

Bulmer, M. (1966) 'The ethnic group question in the 1991 Census of Population', in D. Coleman and J. Salt (eds) *Ethnicity in the 1991 Census* (vol 1, pp 33–62). London: HMSO

Burholt, V. (2004) 'The settlement patterns and residential histories of older Gujaratis, Punjabis and Sylhetis in Birmingham, England', *Ageing and Society*, 24(3), 383–409

Butt, J. and O'Neil, A. (2004) *Let's Move On: Black and Minority Older People's Views of Research Findings*. York: Joseph Rowntree Foundation

Butt, J., Moriarty, J., Brockmann, M., Sin, H.C. and Fisher, M. (2003) *Quality of Life and Social Support among Older People from Different Ethnic Groups*. Sheffield: University of Sheffield. Growing Older Programme Research Findings. Available online at www.shef.ac.uk/uni/projects/gop/GOFindings23.pdf

Cattan, M. (ed.) (2009) *Mental Health and Well-being in Later Life*. Maidenhead: Open University Press

Cattan, M., Kime, N. and Bagnall, A.-M. (2010) *Low-Level Support for Socially Isolated Older People: An Evaluation of Telephone Befriending*. London: Help the Aged

Cattan, M., Newell, C., Bond, J. and White, M. (2003) 'Alleviating social isolation and loneliness among older people', *International Journal of Mental Health Promotion*, 5(3), 20–30

Cattan, M., White, M., Bond, J. and Learmonth, A. (2005) 'Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions', *Ageing and Society*, 25(1), 41–67

Chadha, S. and Young, J. (2002) 'National Service Framework for Older People: will access to health services for elderly patients improve?', *Journal of Disease Management and Health Outcomes*, 10(9), 527–33

Chahal, K. and Temple, B. (2005) 'A review of research on minority ethnic older people', *SAGE Race Relations Abstracts*, 30(4), 3–40

Chalal, K. and Ullah, A.I. (2004) *Experiencing Ethnicity: Discrimination and Service Provision*. York: Joseph Rowntree Foundation

Chiu, S. and Yu, S. (2001) 'An excess of culture: the myth of shared care in the Chinese community in Britain', *Ageing and Society*, 21(6), 681–99

Clough, R., Manthorpe, J., Raymond, V., Sumner, K., Bright, L. and Hay, J. (2007) *The Support Older People Want and the Services They Need*. York: Joseph Rowntree Foundation

Cordingley, L., Hughes, J. and Challis, D. (2001) *Unmet Need and Older People: Towards a Synthesis of User and Provider Views*. York: University of Manchester

Darlow, A., Bickerstaffe, T., Burden, T., Green, J., Jassi, S., Johnson, S., Kelsey, S., Purcell, M., South, J. and Walton, F. (2005) *Researching Bradford: A Review of Social Research on Bradford District.* Leeds: Leeds Metropolitan University

DfT (Department for Transport) (2004) *Tomorrow's Roads – Safer for Everyone: The First Three Year Review: The Government's Road Safety Strategy and Casualty Reduction Targets for 2010*. London: DfT

DH (Department of Health) (1994) *The F Factor: Reasons Why Some Older People Choose Residential Care*. London: DH

DH (2001) *National Service Framework for Older People*. London: DH

DH (2003) *Tackling Health Inequalities A Programme for Action*. London: DH

DH (2004) *Choosing Health: Making Healthier Choices Easier*. London: The Stationery Office

DH (2006) *Our Health, Our Care, Our Say: A New Direction For Community Services*. London: The Stationery Office

DH (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. London: DH

Directgov (2009) *Carer's Allowance – Effect on Other Benefits and Entitlements*. Retrieved from www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/CarersAllowance/DG_10012529

Dunnell, K. (2008) *Ageing and Mortality in the UK: Population Trends*. Basingstoke: Office for National Statistics

DWP (Department for Works and Pensions) (2005) *Opportunity Age*. London: HM Government

Evandrou, M. (2000) 'Social inequalities in later life: the socio-economic position of older people from ethnic minority groups in Britain', *Population Trends*, 101(autumn), 11–18

Fenton, S. (1987) *Ageing Minorities: Black People as they Grow Old in Britain*. London: Commission for Racial Equality

Finch, J. and Mason, J. (1990) 'Gender, employment and responsibilities to kin', *Work, Employment & Society*, 4(3), 349–67

Finch, J. and Mason, J. (1993) *Negotiating Family Responsibilities*. London: Routledge

Franzosi, R. (1994) 'From words to numbers: a set theory framework for the collection, organization, and analysis of narrative data', *Sociological Methodology*, 24, 105–36

Franzosi, R. (2004) *From Words to Numbers: Narrative, Data, and Social Science.* Cambridge: Cambridge University Press

Glendinning, C., Challis, D., Fernandez, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, A. and Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Summary Report*. York: Social Policy Research Unit, University of York

Godfrey, M. and Callaghan, G. (2000) *Exploring Unmet Needs*. York: Joseph Rowntree Foundation

Godfrey, M., Townsend, J. and Denby, T. (2004) *Building a Good Life for Older People in Local Communities*. York: Joseph Rowntree Foundation

Groger, L. (1994) 'Limit of support and reaction to illness: an exploration of black elders' pathways to long term care settings', *Journal of Cross Cultural Gerontology*, 9(4), 369–87

Heenan, D. (2006) 'The factors influencing access to health and social care in the farming

communities of County Down, Northern Ireland', *Ageing & Society*, 26, 373–91

Helgeson, V.S. (2003) 'Social support and quality of life', *Quality of Life Research*, 12, 25–31

Horne, M. and Costello, J. (2003) 'Health needs assessment involving older people in health research', *Quality in Ageing*, 4, 14–22

Hupsey, J.E. (1998) 'Clarifying the social support theory–research linkage', *Journal of Advanced Nursing*, 27, 1231–41

Jarvis, A., Worth, J. and Porter, M. (2006) 'The experience of caring for someone over 75 years of age: results from a Scottish general practice population', *Journal of Clinical Nursing*, 15, 1353–478

JRF (Joseph Rowntree Foundation) (2004) 'From welfare to well-being – planning for an ageing society: summary conclusions of the Joseph Rowntree Foundation Task Group on Housing, Money and Care for Older People', JRF *Findings* (October 2004)

Karn, V., Mian, S., Brown, M. and Dale, A. (1999) *Tradition, Change and Diversity: Understanding the Housing Needs of Minority Ethnic Groups in Manchester*. London: The Housing Corporation

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R. and Parker, G. (2004) 'Do they look after their own? Informal support for South Asian carers', *Health & Social Care in the Community*, 12(5), 398–406

Katbamna, S., Baker, R., Ahmad, W., Bhakta, P. and Parker, G. (2001) 'Development of guidelines to facilitate improved support of South Asian carers by primary health care teams', *Quality in Health Care*, 10(3), 166–72

Lievesley, N., Hayes, R., Jones, K. and Clark, A. (2009) *Ageism and age discrimination in secondary health care in the United Kingdom. A Review of the Literature*. London: Centre for Policy on Ageing

Manthorpe, J. (2008) 'Individual Budgets – the story so far', *Community Care*, 6 November. Available online at www.communitycare.co.uk/Articles/Article.aspx?liArticleID=109880&PrinterFriendly=true

McCann, S., Ryan, A.A. and McKenna, H.P. (2005) 'The challenges associated with providing community care for people with complex needs in rural areas: a qualitative investigation', *Health and Social Care in the Community*, 13, 462–69

Merrell, J., Kinsella, F., Murphy, F., Philpin, S. and Ali, A. (2005) 'Support needs of carers of dependent adults from a Bangladeshi community', *Journal of Advanced Nursing*, 51(6), 549–57

Merrell, J., Kinsella, F., Murphy, F., Philpin, S. and Ali, A. (2006) 'Accessibility and equity of health and social care services: exploring the views and experiences of Bangladeshi carers in South Wales, UK', *Health and Social Care in the Community*, 14(3), 197–205

Modood, T. (1997) 'Qualifications and English language', in T. Modood, R. Berthoud, J. Lakey, J. Nazroo, P. Smith, S. Virdee and S. Beishon (eds) *Ethnic Minorities in Britain: Diversity and Disadvantage* (pp 60–82). London: Policy Studies Institute

Moffatt, S. and Higgs, P. (2007) 'Charity or entitlement? Generational habitus and the welfare state among older people in North-East England', *Social Policy Administration*, 41 (5), 449–64

National Statistics (2003) *Ethnicity, Population Size*. 13 February 2003. Retrieved from www.statistics.gov.uk/CCI/nugget.asp?ID=273

Neufeld, A., Harrison, M.J., Stewart, M.J., Hughes, K.D. and Spitzer, D. (2002) 'Immigrant women: making connections to community resources for support in family caregiving', *Qualitative Health Research*, 12(6), 751–68

Older People's Steering Group (2004) *Older People Shaping Policy and Practice*. York: Joseph Rowntree Foundation

Outside Research and Development (2006) *Care Needs of Older People in Manningham*. Leeds: Outside Research and Development

Owens, A. and Randhawa, G. (2004) '"It's different from my culture; they're very different": providing community-based, "culturally competent" palliative care for South Asian people in the UK', *Health and Social Care in the Community*, 12(5), 414–21

Phillipson, C., Bernard, M., Phillips, J. and Ogg, J.I.M. (2000) 'The family and community life of older people: household composition and social networks in three urban areas', *Ageing and Society,* 18(3), 259–89

Quinn, A., Snowling, A. and Denicolo, P. (2003) *Older People's Perspectives: Devising Information, Advice and Advocacy Services*. York: Joseph Rowntree Foundation

Qureshi, H. and Walker, A. (1989) *The Caring Relationship: Elderly People and their Families*. Philadelphia, PA: Temple University Press

Rai-Atkins, A. (2002a) *Best Practice in Mental Health: Advocacy for African, Caribbean and South Asian Communities*. York: Joseph Rowntree Foundation

Rai-Atkins, A. (2002b) 'Mental health advocacy for black and minority ethnic users and carers', JRF *Findings* (March 2002)

Raynes, N., Clark, H. and Beecham, J. (2006) *The Report on the Older People's Inquiry into 'That Bit of Help'*. York: Joseph Rowntree Foundation

Raynes, N., Margiotta, P., Lawson, J. and Pagidas, D. (2003) 'The provision of information and advice for older people: what more do they want?', *Quality in Ageing*, 4(3), 23–9

Raynes, N., Temple, B., Glenister, C. and Coulthard, L. (2001) *Quality at Home for Older People: Involving Service Users in Defining Home Care Specifications*. Bristol: The Policy Press

Scheppers, E., van Dongen, E., Dekker, J., Geertzen, J. and Dekker, J. (2006) 'Potential barriers to the use of health services among ethnic minorities: a review', *Family Practice*, 23(3), 325–48

Seabrooke, V. and Milne, A. (2004) *Culture and Care in Dementia: A Study of the Asian Community in North West Kent*. Greenhithe: Mental Health Foundation

Seddon, D., Robinson, C., Bowen, S. and Boyle, M. (2004) 'Supporting carers in paid employment developing a needs-led approach', *Quality in Ageing*, 5, 14–23

SEU (Social Exclusion Unit) (2006) *A Sure Start to Later Life: Ending Inequalities for Older People*. London: Office of the Deputy Prime Minister

Sin, C.H. (2006) 'Expectations of support among White British and Asian-Indian older people in Britain: the interdependence of formal and informal spheres', *Health & Social Care in the Community*, 14(3), 215–24

Sin, C.H. (2007) 'Older people from White-British and Asian-British backgrounds and their expectations for support from their children', *Quality in Ageing*, 8(1), 31–41

Spitzer, D., Neufeld, A., Harrison, M., Hughes, K. and Stewart, M. (2003) 'Caregiving in transnational context: my wings have been cut; where can I fly?', *Gender and Society*, 17(2), 267–86

Sproston, K. and Nazroo, J. (eds) (2002) *Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC)*, London: The Stationery Office

Tanner, D. (2001) 'Good practice in prevention', in V. White and J. Harris (eds) *Developing Good Practice in Community Care: Partnership and Participation* (pp 112–31). London: Jessica Kingsley Publishers

Tanner, D. (2003) 'Older people and access to Care', *British Journal of Social Work*, 33(4), 499–515

The Princess Royal Trust for Carers (2005) *Who is a Carer?*. Retrieved from www.carers.org/

Unity Sale, A. (2008) *Commissioning is Key to Personalisation Agenda*. Available online at www.communitycare.co.uk/Articles/2008/11/20/109996/commissioning-is-key-to-personalisation-agenda.html

Victor, C., Scambler, S.J., Bowling, A. and Bond, J. (2005) 'The prevalence and risk factors for loneliness in later life: a survey of older people in Great Britain', *Ageing and Society*, 25(3), 357–75

Wengraf, T. (2001) *Qualitative Research Interviewing: Biographic Narratives and Semi-Structured Methods*. London: Sage Publications

WHO (World Health Organization) (2002) *Active Ageing: A Policy Framework*. Geneva: WHO

Yeatts, E., Crow, T. and Folts, E. (1992) 'Service use among low-income minority elderly: strategies for overcoming barriers', *The Gerontologist*, 32(1), 24–32

Yu, W.K. (2000a) *Chinese Older People: A Need for Social Inclusion in Two Communities*. York: Joseph Rowntree Foundation

Yu, W.K. (2000b) *Meeting the Needs of Chinese Older People*. York: Joseph Rowntree Foundation

Appendix 1
Methods

Recruitment

The study focused on four geographical areas of Bradford, which broadly overlapped with the following four wards: Shipley, Manningham, Little Horton and the City. These were chosen on the basis of the following three criteria:

- the level of deprivation of different wards, as measured by the Indices of Deprivation 2004 at the Super Output Area level;

- an analysis of ethnicity and age at the Super Output Area level;

- consultations with community groups and the members of the Project Advisory Group.

The four chosen areas offered a good balance of individuals belonging to well-established minority ethnic groups, more recent migrant groups and the White British majority. The informal carers recruited for this study did not have to live in the four mentioned areas, as long as the older person who they cared for did.

A breakdown by the age, gender, location and ethnicity of the study participants can be found in Appendix 2.

Data collection

The interview schedules for both the focus group and the individual interviews were written following the algorithm 'research questions → theoretical questions → informant questions' suggested by Wengraf (2001). This approach addresses the question of the operationalisation of concepts in qualitative research (Wengraf, 2001). It points out the necessity of clearly linking the informant questions to the concepts and research questions that they try to answer. In a nutshell, the approach, first, suggests defining the 'central research questions' behind the study. Second, it suggests spelling out the central research questions in

several 'theory questions' that the researcher wants the interviewees to help answer. Finally, for each theory question, the researcher needs to develop suitable sets of interview questions appropriate for the interviewees (Wengraf, 2001).

The interview schedules generated following this approach were then discussed with the Project Advisory Group members, the Steering Group members and the interpreters and improved according to the feedback received.

In the focus group interviews, case studies, in the form of vignettes, were used to stimulate the discussion and to ensure understanding and articulation of the issues being explored. These were well received by the study participants as they enabled them to contribute to the discussion without disclosing personal experiences unless they chose to do so.

Analysis

Both the focus group and the individual interviews were transcribed verbatim. The analysis and interpretation of the transcripts of the focus group interviews were based on 'framework analysis'. This approach to qualitative data analysis is based on five recursive phases:

- *Familiarisation with the collected data*. This was achieved by listening to the audiotape of each focus group interview within 24 hours of its recording and by reflecting on observational notes taken during each section.

- *Construction of an 'indexing table' (also called a 'coding table')*. This was based on issues and questions derived from the literature review, aims and objectives of the study, and recurring views and experiences of the study participants. Examples of codes in our 'index table' are 'Everyday life difficulties', 'Things would like to do but can't', 'Help from family', 'Help from services', 'Expectations about services' and 'Cultural issues'.

- *'Indexing' or 'coding' the data.* This was done by applying the thematic framework/index systematically to all the text of the transcripts with the help of the software Nvivo 7.0. So, single or multiple passages of text were electronically associated to different items or 'codes' of the thematic framework.

- *Charting.* This phase consisted of a twofold process:

  – The creation of a number of charts that had the function of representing key subject areas or themes identified through the indexing process. The rows of the charts consisted of each single focus group interview, whereas the columns consisted of subthemes of the main topic represented by the chart. For example, one chart was titled 'Service and help provision' and had the following subthemes (columns): Help_ Current main sources, Community support_ Attitude, Social care_Attitude, Housing_ Attitude, Reasons for taking up services, Reasons for not taking up services).

  – Sorting the data in each chart by means of distilled summaries of the participants' views and experiences. The data was sorted in each chart after having retrieved, explored and synthesised the text associated with each 'code' of the 'indexing table'. This process was facilitated by the use of the software Nvivo. The advantage of using such software over more traditional methods such as 'cut and paste' is that the researcher does not lose site of the context from which the coded text come.

- *Mapping and interpretation.* In this phase the summaries contained in each chart were used to find associations between themes with a view to providing explanations for the findings. So, for example, the analysis of the content of the charts 'Service and help provision', 'Dissatisfaction', 'Preferences and suggestions about services', and 'Elders' needs' led, together with findings from the individual interviews, to the identification of the themes

'Eligibility', 'Good practice', 'Not value for money' and 'Accessibility'.

The narrative approach of the in-depth interview requires sensitivity to the interview process and the responses. In the interview, the interviewee tells a story, thereby constructing a social reality that is 'meaningful'. The analysis needs to be theoretical, in that themes are drawn from the realities of the social and cultural world of the interviewees. It is not simply about *what* people say but also about *how* they express their experiences, desires and so on. This process of analysis is particularly suited to qualitative research where it is likely that those involved have very different life experiences and social realities. A systematic approach to analysing the study participants' narratives in order to discover the patterns and regularities within their interviews was devised on the basis of the methodology of Franzosi (1994, 2004). This method implied at first defining the subject, the action and the social actors (e.g. family, friends and neighbours) mentioned by the study participants within their narrative clauses concerning experiences of help, care and support; then subsequently examining the social actors most commonly involved in experiences of help and support in the different groups of interviewees, and how those social actors were described in the narratives of older participants of different backgrounds.

Appendix 2
Characteristics of the older people interviewed

Table A1: Age groups

Age group	Frequency	%
25–35	5	2.94
36–45	7	4.12
46–59	21	12.35
60–65	14	8.24
66–70	43	25.29
71–75	27	15.88
76–80	26	15.29
81–90	22	12.94
Missing values	5	2.94
Total	170	100

Table A2: Gender

Gender	Frequency	%
Female	127	74.71
Male	43	25.29
Total	170	100

Table A3: Location

Location	Frequency	%
BD1–BD3, BD4 (City and Bowling)	32	18.82
BD5, BD7 (Great Horton)	41	24.12
BD6–BD7	39	22.94
BD8–BD9 (Manningham)	16	9.41
BD18 (Shipley)	7	4.12
BD21 (Keighley)	10	5.88
BD12, BD13, BD14, BD15, BD16, BD17	16	9.41
BD19, BD20, BD22	5	2.94
Missing values	4	2.35
Total	170	100

Table A4: Ethnicity

Ethnicity	Frequency	%
White British	37	5.29
Irish	3	21.76
Polish	15	8.82
Ukrainian	12	1.76
Italian	21	4.12
Hungarian	9	20.00
Pakistani	34	11.18
Indian	13	12.35
Bangladeshi	19	7.65
African Caribbean	7	7.06
Total	170	100

Appendix 3
Interpreter workshop

Sixteen interpreters were involved in the study to assist the study participants who were not fluent in or did not speak English during the focus groups and the individual interviews. The interpreters were recruited through the Bradford Interpreting Unit. A two-day research training workshop was organised with the interpreters to:

- introduce them to the research project;

- provide them with interview skills;

- have an opportunity to include their views regarding the research.

The first day of the workshop was devoted to introducing the research project to the interpreters and to carry out a range of activities aimed at eliciting the interpreters' views about:

- what a good interpreter was;

- what a good researcher in a cross-language setting was.

This allowed the research team to identify the beliefs and expectations of the interpreters about their role, the research and the research team themselves.

During the second day of the workshop a second set of activities was carried out involving case scenarios about ethical issues in the research process, for example older people's consent to take part in the study and disclosure of personal information. The interpreters were also asked to comment on both the interview schedule for the focus group and the interview schedule for the individual interviews. These two sets of exercises allowed the research team to clarify ethical responsibilities with the interpreters and also to learn about a number of potential issues concerning the translation of some words in certain languages, for example the word 'carer'. The discussion of these issues was highly beneficial in helping to improve the clarity of the interview schedules and in strengthening the inclusion of the interpreters as co-researchers.

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