Satisfaction with social care services among Black and Minority Ethnic populations.

Exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people.

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This work was carried out in collaborations with Prof. Alison Bowes from the University of Stirling and Ghazala Mir from the University of Leeds

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Summary

Study design
Black and minority ethnic recipients of local authority funded adult social care services consistently report lower satisfaction than white British service users with the service and care they receive. The aim of this project was to provide explanations for the reasons behind these lower levels of satisfaction.

This study focused on two particular ethnic groups: Pakistani and Bangladeshi. White British people were also included as a comparison group. The study had five key stages:

Stage 1: literature review;
Stage 2: qualitative in-depth interviews with social care recipients and their families across the three ethnic groups;
Stage 3: cognitive interviews with social care recipients and their families;
Stage 4: focus groups and in-depth interviews with local authority staff and social care providers;
Stage 5: deliberative workshops with practitioners and users to develop recommendations for meeting diverse user needs.

The objectives of the research were to:
- Explore expectations and experiences of Pakistani, Bangladeshi and white British social care service users;
- Explore how users understand and respond to questions that measure satisfaction with social care and the extent to which they produce comparable data within and between groups;
- Understand the context within which social care providers (care and support workers, voluntary and community organisations, local authority managers of social care and social workers) work with diverse groups;
- Make recommendations about the delivery of social care and the design of satisfaction surveys based on our findings.

Key findings
Overall, there were similarities in the drivers of satisfaction and dissatisfaction across Pakistani, Bangladeshi and white British groups. Service users were more likely to be satisfied when they were able to access the care package they needed and care workers completed tasks competently, on time but without rushing and with a good and caring attitude. The main area for concern and dissatisfaction across ethnic groups was a need for more care or local authority funded services. There was an awareness of the austerity
measures local authorities were under; participants therefore felt that further funding for care would be unlikely whilst their need would remain. This finding cut across ethnic groups.

Nonetheless clear findings did emerge specifically related to culture, language and religion which did affect service users’ experience of care services. Service users of Pakistani or Bangladeshi origin and their families were grateful for the care and financial support they received. The issues that Pakistani and Bangladeshi participants reported, which were different from those reported by white British service users, were subtle and often specific to the circumstances of the individual.

A clear difference between participants was those who were able to negotiate the care system and those who found it challenging. Pakistani and Bangladeshi groups encountered a number of barriers to accessing care from local authorities. Factors such as education, whether they were first or second generation migrants and language skills were important in understanding how Pakistani and Bangladeshi participants experienced the social care system.

Pakistani and Bangladeshi service users were more likely than white British service users to live with their families. For some Pakistani and Bangladeshi participants there was a desire (and in some instances a pressure) for care to be provided by family members. This was sometimes combined with discomfort about receiving ‘outside’ care, as well as a belief that local authorities were less likely to provide support to South Asian service users because they lived with their families; as a result formal care support was often only sought at crisis point.

Cultural and faith values were, for some, intertwined with their expectations and needs for homecare. Pakistani and Bangladeshi service users and families sometimes had unrealistic expectations (both very high and low) of paid homecare. Ethnic matching between service users and care workers was widespread; but not all service users or families wanted a care worker from their community. Considering the needs of the family, as well as the individual service user was more important in determining satisfaction among Bangladeshi and Pakistani groups than among white British.

A detailed summary is provided below.

Participant characteristics and their care scenarios

- Overall, 61 service users and/or relatives were interviewed. Participants were aged 18 and over, had a range of health conditions and were of Pakistani, Bangladeshi or white British ethnicity. Participants lived across three areas of England: London, Birmingham or Leeds.

- Participants were in receipt of local authority funded adult social care. The sample also included participants who were either in the process of applying for social care at the time of interview or had been in receipt of care in the previous 12 months.
Participants had a range of different care packages. Homecare was the most common form of formal care, followed by attendance at day opportunities services and home adaptations. The sample included participants who were in receipt of personal budgets.

Relationships with local authorities and accessing care

There was widespread confusion about the organisation of adult social care services among all three ethnic groups, but particularly among Bangladeshi and Pakistani service users and their relatives.

Relatives of Bangladeshi and Pakistani service users had often struggled on their own for years before finding out about adult social care services. They faced a mixture of educational, language and cultural barriers to obtaining information. They were more likely than white British people to have been unaware of the services offered by local authorities.

There were complaints about poor communication by local authorities among all three ethnic groups. Local authority staff believed that a shift from face-to-face communication to telephone contact centres presented particular problems for people who did not speak fluent English.

Local authorities acknowledged that they needed to engage with local communities, in order better understand their needs of and raise awareness of services and support available.

Service users and relatives from all three ethnic groups alluded to a need to ‘fight’ for services. Bangladeshi and Pakistani families who did not speak fluent English found it extremely challenging to argue their case. Among Bangladeshi and Pakistani service users and relatives there were those who expressed gratitude for receiving any services at all, while others had unrealistic expectations of what local authorities could provide, perhaps because of communication problems and a misunderstanding of the scope of local authority provided social care.

The desire to care for one’s own family members without help from external agencies was expressed by some, though not all, service users of Pakistani and Bangladeshi origin. As a result there were concerns, particularly from other family members, about allowing an ‘outsider’ to enter the home and provide care, particularly personal care. There was also some concern about the stigma associated with receiving help from outside.

There was a perception among relatives of Bangladeshi and Pakistani service users that local authorities were reluctant to provide a high level of formal care to people living with their families. This was felt to be unfair for South Asian South Asian families, who were seen as more likely
than white British families to be sharing their homes with older and disabled relatives.

- People from all three ethnic groups talked about the importance of a sustained relationship with a competent social worker. Bangladeshi and Pakistani service users and relatives did not necessarily expect their social worker to speak their language, but they did want them to show cultural sensitivity and to use an interpreter if necessary.

- Personal budgets were attractive for Pakistani and Bangladeshi service users because they allowed them to employ carers of their choice and avoid the stigma of receiving care from non-family members, but the associated administration was confusing, especially for people who were not fluent in English or a who had low level of education.

- Providers said that they received limited information on service users from local authorities at the referral stage that could be helpful in meeting needs, and the type of information differed from one local authority to another.

Receiving care

- Having a good relationship between the service user and care worker, was an important factor to being happy with the care being received. Service users and relatives placed importance on a sustained relationship with a competent care worker.

- Service users and relatives expected care workers to be both professional and personable. Completion of required care tasks was not enough to achieve satisfaction; being friendly and caring helped to establish a human relationship. South Asian participants placed greater emphasis on having a care worker who completed the tasks well; whilst having a chatty or friendly care worker was particularly important amongst white British service users.

- Experiences of poor professional conduct of care workers, for example, falsifying timesheets was not widespread but was damaging to confidence in formal social care services.

- Having a shared language with care workers enabled service users or relatives to instruct staff with ease and aided rapport.

- Care workers were under demanding time pressures. Time allocated for completing tasks was often tight or insufficient, as was travel between clients. This resulted in tasks not being completed, or service users feeling care workers were rushing and did not care about the work be done.

- Homecare provider managers and care workers believed that the best way to meet the needs of service users from different ethnic groups was to match care workers to service users on ethnicity, gender and
language. None of the providers that took part in this study offered training on culturally-sensitive care.

- Ethnic specialist day opportunities services facilitated social contact with peers, culturally appropriate activities and foods. **Ethnic specialist day services in themselves, however, were not a source of satisfaction.** Poorly run services resulted in dissatisfaction. Supportive and engaging staff and having a range of activities available remained important across ethnic specialist and generic services.

- Asian specialist day services acted as a bridge between social services and Bangladeshi and Pakistani service users and relatives, assisting them in understanding and navigating the local authority care system.

- A main cause for dissatisfaction among service users and relatives was that they required more homecare, and either had not been able to or did not know how to obtain this. Unmet needs were common amongst those who found the social care system hardest to negotiate; including Pakistani and Bangladeshi participants who were not fluent in English or were otherwise disadvantaged.

- Loneliness and isolation were widespread and represented a major unmet care need. Outside of day opportunities services, this care need was not catered for by local authority funded services.

**Cultural background and satisfaction with care**

- For some Pakistani and Bangladeshi participants, cultural practices and faith based values were intertwined; they influenced expectations of and satisfaction with the care they received. This could affect whether faith or language matching was desired, and led to preferences for care which was compatible with their practices (e.g. prayer or food).

- A number of common cultural factors that influenced expectations of care were identified. These included the involvement and influence of family members, socio-economic status and levels of education. Differences were also apparent between those participants who had recently migrated and those who were born or had lived in the UK for a significant length of time. **Those more proficient in English had a better understanding of their entitlement to care and they were better at negotiating the care system.**

- There were tensions within families from all three ethnic groups as a result of service users being reliant on care provided by family members. **Carers found their role exhausting**, especially if they were working or had young children. **These tensions were especially evident among Bangladeshi and Pakistani families, where most caring was done by women.**

- There were concerns expressed by social workers and providers about Pakistani and Bangladeshi women, who were acting as main informal
care givers, and struggling to cope. These women typically did not speak English fluently, may not have disclosed to family members that they required help, and may not have known about availability of formal services or how to access them. Social workers expressed concern about their experiences of being unable to speak to the women providing informal care because of language barriers and other commitments for carers (such as childcare). Female carers indicated that they needed more help but did not know how to go about getting it and also commented on the need for help from family in communicating with English speakers.

- Care providers advocated having an open discussion about the characteristics service users and their relatives did or did not want in a care worker; including preferred gender, ethnicity and language of a care worker. The reasons given by those users and relatives who did desire ethnic matching were twofold – firstly, an increased level of familiarity because of shared cultural factors, and secondly the expectation of a more tailored level of care with potential practical and social benefits. However, ethnic matching was not desired by all; in order to maintain privacy and confidentiality, some Pakistani and Bangladeshi families requested a care worker from a different ethnic or community group from their own.

**Recommendations**

Discussion of the key findings of this project at three deliberative workshops in autumn 2013 resulted in a number of recommendations:

- Local authorities and providers could engage with minority communities, through the media and community organisations to raise awareness of available services and reduce the stigma associated with accessing services

- Service user characteristics and preferences should be taken into account when choosing a package of care to ensure that there is cultural and religious sensitivity, but misplaced assumptions are not made. This would require open discussions between the local authority and providers and between providers, service users and their families.

- Communication with those who do not speak English fluently could be improved through workforces that are representative of local populations, greater use of interpreters and better briefing and training of both interpreters and social workers.

- Action to ensure that the care workforce reflects the ethnic mix of the local service user population would need to include making this a more attractive job for people from minority groups.

- Improved and ongoing training for social workers and care workers on cultural issues relevant to the local population and on how to develop a service user led understanding of needs may improve relationships with service users.
• There needs to be an understanding of the gender dimension to care and how this interacts with cultural, religious and ethnic differences. Carer and care and support worker populations are predominantly women, and cultures and religions vary in terms of expected and appropriate roles for women. This means that in engaging with minority communities, expanding the workforce and meeting the needs of individual service users, the impact on and role of women needs to be actively considered.
1 Introduction

1.1 Overview of the research

People from Black and minority ethnic (BME) groups consistently report lower levels of satisfaction with adult social care than white British people. As a result, the National Institute for Health Research (NIHR) School for Social Care Research (SSCR) called for research to explore the reasons for this.

This research employed two distinct methods: qualitative in-depth interviews and cognitive interviews, to address two different questions and understand the reasons underlying lower reported satisfaction in the Health and Social Care Information Centre Adult Social Care Surveys (NHS Information Centre, 2012). The qualitative element allowed for exploration of whether lower satisfaction was related to how social care is delivered to or received by BME groups. The cognitive element allowed exploration of how the survey questions are understood or answered by different groups and whether differences in satisfaction data reflect inconsistencies in the measurement of satisfaction between groups.

Whilst this research focused on two ethnic minority groups, Pakistani and Bangladeshi, it is likely that some of the findings will be more generally applicable to other BME groups.

Qualitative research

This report focuses on the qualitative aspect of the study to explore underlying reasons for lower satisfaction among particular groups; further detail about the approach and findings are outlined in the rest of the report.

Cognitive research

The cognitive element of the research explored whether existing surveys are effectively capturing differing levels of satisfaction with social care. Cognitive interviews uncover the processes going on when people respond to survey questions. These interviews were used to explore how respondents understand survey questions, recall the information needed, make judgements about how to respond, and use the response categories provided. By using this technique to test the standard questions used in the Adult Social Care Survey, we aimed to explore whether questions were understood and answered in a consistent manner across groups and accurately reflect satisfaction levels.

The cognitive element of this project provided an understanding of whether the tools currently used are effectively giving a voice to the experience of Pakistani and Bangladeshi groups where language or cultural differences may affect how people respond to questionnaires (though they are available in minority languages).
We conducted over 30 cognitive interviews with service users and relatives. We found that questions were understood in a consistent way across the three ethnic groups. Issues were found with the suitability of existing translations, the use of some phrases in questions and the role of family members and care workers in assisting with completion. However there was no evidence of systematic inconsistency in the data collected from the three ethnic groups included in this study. There is a separate report detailing the cognitive element of this research (Gray et al, 2014).

**Recommendations**

The final stage of the project was a series of deliberative workshops, a participatory approach that actively involved stakeholders within social care to assist in the formulation of recommendations to improve social care for minority groups. We presented preliminary findings from the qualitative research and the cognitive research into survey questions to a range of practitioners and service users and then facilitated discussion on the implications. Recommendations are presented within this report, and include recommendations for both satisfaction surveys and the organisation and provision of adult social care.

1.2 **Report structure**

This report is made up of six chapters.

Chapter 2 provides detail on the background to the project and methodology used across the whole project.

The substantive chapters in this report present the qualitative element of the project with a focus on exploring what drives satisfaction with social care.

Chapter 3 outlines the characteristics of the research participants and the types of living arrangements and care packages service users were in receipt of. Receipt of care provided by the family is also covered as this was an integral part of the overall care people received.

Chapter 4 discusses the experiences people had of accessing local authority social care services. We outline the facilitators and barriers in negotiating the adult social care assessment process, as well as people’s relationships with social workers.

Chapter 5 describes people’s views and experiencing of receiving care services; and the aspects of local authority funded social care that drive satisfaction with social care. Both in home and out of home care are discussed.
Chapter 6 provides a discussion of the overarching issues affecting satisfaction with social care, with a particular focus on cultural, language and religious factors, along with a set of recommendations for working with BME service users based on the deliberative workshops.

There are two separate reports associated with this project:

- A literature review of the key literature related to cultural and faith differences in health and social care, and the methodologies for qualitative research with BME groups (Bowes et al, 2012).
- A report of the findings from the cognitive interviewing element of the project (Gray et al, 2014).

1.3 A note on language

Throughout the report we use the terms ‘care and support worker’ or ‘care worker’ to describe professional care workers. The term carer is only used to describe a family member or friend providing care or is used in quotes where used by participants who used the term interchangeably to describe family carers as well as care and support workers. Where we use the term ‘informal’ care this means care from a family or friend, as distinct from ‘formal’ care paid for by the local authority or the service user. In practice, these distinctions are not always clear-cut, where family members are paid to provide care through personal budgets. We are aware that the terms we have used are not necessarily those which services users or their families would use, however we have used them to provide consistency through the report and clarity to the reader about what we mean.
2 Background and Study design

This research was commissioned by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The aim was to understand the reasons for lower satisfaction with social care amongst Pakistani and Bangladeshi people compared with white British people.

2.1 Background

Despite the existence of a long-established and diverse BME population in the UK, providing satisfactory health and social care services to different ethnic groups remains a challenge. Patient experience surveys have been carried out for several years with large samples and provide data on satisfaction with various aspects of NHS services broken down by ethnicity. There are fewer data available on satisfaction with social care services. Until recently surveys on social care have focused on particular aspects of the service (e.g. equipment use in 2007-8 and older people in 2008-9). Since 2009 new surveys for social care have been developed with the intention that data will be available across all aspects of social care use every year and in order to better understand how the personalisation of services is affecting people’s lives (Health and Social Care Information Centre, 2013). For example in 2011-12 while 64% of white respondents reported being extremely or very satisfied with the services received, 51% of Asian and Asian British and 53% of Black and Black British reported this (NHS Information Centre, 2012) and similar results emerged from the 2012-13 Adult Social Care Survey.

Beyond these data, the literature highlights the complex and multi-dimensional nature of these issues and the continuing need for research in critical areas. Much of the literature focuses on health services, but the findings are relevant to social care. Issues include persistently unresponsive services (e.g. Bowl, 2007 on mental health services); staff who feel ill-equipped to address diversity issues (e.g. Richardson et al, 2006); services that fail to engage with minorities (e.g. Cooper et al, 2010, Manthorpe et al, 2009); assumptions about cultural practices that prevent genuinely sensitive service provision (e.g. Chau and Yu, 2009); and a continuing predominance of approaches which fail to appreciate intra-ethnic diversity (Williamson and Harrison, 2010) and the need to treat service users as individuals. Croot (2012) found that a concept of ‘cultural competence’ (Yeowell, 2010) can be problematic if it stereotypes the views of people from different ethnic backgrounds. Jirwe et al, 2009 consider that care needs to be responsive to cultural practices, it is not enough to know about them.

There is also evidence of poor uptake of health services, either because people do not seek help or because services are not receptive to them (Hanley, 2007, Mir and Sheikh, 2010). Not seeking help can be related to people seeing problems as normal and not something for which they can get help (Wells and Wagg, 2007), and also because of the
stigma attached to seeking help (Knifton, 2012 in the context of mental illness and Singh, 2012 in the context of diabetes).

Overall the literature highlights that the impacts of culture are nuanced and interact with other influences. This means that sometimes ethnicity makes a difference and sometimes it does not. Service provision can be informed by similarities between groups, as well as differences (Parveen et al, 2011). The changing policy context of social care provision with the rise of individualised care means that there is an opportunity for people to specify the services they actually need, rather than the old ‘one size fits all’ approaches of both generic and ‘culturally specific’ service provision (Gask et al, 2011). The evidence also suggests a need for co-produced care in which ‘reflective practitioners’ deliver services in a way which is more appropriate for people's beliefs and expectations, and which acknowledges religious and cultural considerations (Almond and Lathlean, 2011; Atkin and Chattoo, 2007; Mir and Sheikh, 2010).

There is a considerable literature concerning the comparability of survey questions across cultures and languages (both cross-nationally and within an individual country). This includes the question of whether concepts can transfer effectively cross-culturally (Warnecke et al, 1997; Hunt and Bhopal, 2004). All quantitative survey research relies on the assumption that questions are asked and understood in a consistent manner and that data can be treated as comparable in analysis. Where survey questions are culturally non-equivalent this can lead to systematic measurement error in data collection. Even where concepts are considered to be universal (etic) the way in which they are expressed or constructed may vary. For example, ‘health’ may be a universally accepted concept but the extent to which various elements of health (physical, mental and spiritual) are considered may vary. There is now emerging evidence that widely used questions such as that used to ask about general health do not work in an equivalent way across cultures (Shoua-Glusberg and Hinsdale-Shouse, 2010). There is also research evidence about how different groups respond to certain types of survey questions. For example Warnecke et al (1997) argue that Asian participants avoid extreme responses (based on research in the US) and cross-national research has also shown that rating behaviour using standard scales varies between languages and cultures (Mohler et al, 1998).

These two strands guided the design of this research project:

- one, the way in which services may be provided to and received by different communities, and
- two, the way in which surveys may collect inconsistent data from different groups.

### 2.1.1 Pakistani and Bangladeshi communities

As detailed above, data from the Health and Social Care Information Centre Adult Social Care Surveys show lower levels of satisfaction among the Asian and Asian British groups compared with white British (The NHS Information Centre, 2012). However, as highlighted by the wider literature, this does not take into account the diversity of culture, religion and language within the Asian groups nor diversity in experience of social care services. To
explore the issue fully we needed to focus on particular groups to reduce the degree of heterogeneity among participants.

We chose to focus on the Bangladeshi and Pakistani communities for a number of reasons including poor indicators on other aspects of health and wellbeing for these groups. For example, in the Health Survey for England 2004 (Sproston and Mindell, 2005), Pakistani women and Bangladeshi men were more likely than those in the general population to report a limiting longstanding illness and a lack of social support was particularly marked among Bangladeshi and Pakistani participants. Particularly in relation to social care use, faith identity is likely to be important. Research has shown that although health and social inequalities are usually explored in terms of ethnicity, faith identity is extremely important and neglected in the research (Mir and Sheikh, 2010). In this project, by focussing on two populations which are predominantly Muslim it was possible to explore the relative importance of religion and culture as well as diversity among individuals within those groups in influencing experience of using social care services.

There are also more likely to be language and communication problems among the Pakistani and Bangladeshi communities (than some other groups) in accessing and using social care services (Mir and Sheikh, 2010) which may be relevant in relation to satisfaction. Those who prefer to use languages other than English or do not speak English at all are likely to report more problems with communication and discrimination. Furthermore, their conceptualisations of satisfaction are likely to be shaped by the cultural values inherent in language. Although satisfaction questionnaires are offered in translation, the cultural assumptions underlying the questions may not have been translated.

We included a white British comparison group both as a reference point against which to compare findings from the Pakistani and Bangladeshi communities but also to explore the extent to which there is diversity within communities which may cut across ethnic and faith identities.

### 2.2 Aims and Objectives

Within this project we aimed to provide explanations for the reasons behind lower levels of satisfaction reported by BME recipients of social care services by focusing on two particular groups (Pakistani and Bangladeshi) and social care received by people living in the community. The focus of this project was on people who use social care services provided by or funded by local authorities. The Adult Social Care Survey findings which prompted this project only cover local authority care. As is clear from our findings, people also receive care and support from relatives, as well as from private providers paid for by the service user and these are an integral and important part of the care they receive.

The four main objectives of the research were to:
1. Explore the underlying reasons for lower levels of satisfaction with social care among BME groups by focusing on two particular groups: Bangladeshi and Pakistani. The underlying issues to be explored included:

- difficulties in accessing care;
- reluctance to access care, leading to unmet need for care;
- inconsistencies in the quality of care provided;
- consistent but inappropriate care provision;
- differing expectations;
- socio-demographic or geographical differences;
- the types of services needed.

2. Understand how different groups go about responding to social care satisfaction questionnaires and explore whether this results in inconsistencies in the resulting data when comparing satisfaction between groups.

3. Understand the context in which social care is provided from the perspectives of local authorities, individual workers and provider organisations.

4. Make practical recommendations on:

- how changes in service delivery could improve satisfaction;
- how changes to the survey questions could improve consistency of the measurement of satisfaction between groups.

### 2.3 Study Design

The study took place over a two year period (2012-2013). It had five key stages, involving a range of stakeholders, in order to provide a comprehensive understanding of the context in which adult social care is provided and received among BME groups:

**Stage 1: Literature review**
A systematic review of literature on social care use among BME groups and issues surrounding conducting research with these groups. Although selected literature is referred to in this report, a separate literature review (Bowes et al, 2012) is also available with the detail of the methods used.

**Stage 2: Qualitative fieldwork, in-depth interviews with social care recipients and their families**
In-depth interviews with Pakistani, Bangladeshi, and white British service users and their families to explore cultural and personal expectations and experiences of accessing and receiving social care. The focus of these interviews was understanding the drivers of satisfaction and dissatisfaction through exploring in depth how care is received by service users.
Stage 3: Cognitive interviews with social care recipients and their families
Cognitive interviews with Pakistani, Bangladeshi, and white British service users and their families to explore use of language and ways of reporting experience and the extent to which satisfaction surveys produce comparable data within and between groups. These interviews with service users and their relatives focussed on testing questions about satisfaction and quality of care from the Health and Social Care Information Adult Social Care Survey. 34 interviews were conducted with social care service users and their relatives (individual and paired interviews as appropriate). Full details of the design and findings of the cognitive interviewing element of this project are contained within a separate report (Gray et al, 2014)

Stage 4: Qualitative fieldwork, focus groups and in-depth interviews with social care providers
Focus groups and in-depth interviews with staff responsible for managing or providing social care. Specifically, key informant interviews with managerial staff within local authorities and provider care provider organisations; and focus groups with social workers and homecare workers providing domiciliary care to provide a understanding of the context and ensure that recommendations are relevant and appropriate.

Stage 5: Deliberative workshops
Deliberative workshops to share research findings (from stages 1-4) with practitioners and service users to develop recommendations for meeting diverse user needs effectively.

2.4 Advisory group
Throughout the research we involved a range of stakeholders through an advisory group to ensure that the research addresses salient issues, produces findings which stand up to scrutiny and develop recommendations which are appropriate and will engage those responsible for making changes. Members included academics, service providers and service users. The advisory group was convened at three points across the project lifespan to support and make recommendations to the research team. These key points were: one, at the initial design stage, to agree on the sampling and recruitment design and advise on the topic guide; two, once we had completed the literature review and fieldwork had commenced, and to advise on the design of the cognitive interviewing; three, to discuss the emerging findings and plan the deliberative workshops.

2.5 Ethics and quality assurance
Prior to starting project work, an application was made to the Social Care Research Ethics Committee and approval was given. Throughout the project we maintained contact with the Social Care REC to discuss ethical issues which arose and to apply for amendments, as needed. Additionally, all interviewers had enhanced Criminal Records Bureau (CRB) clearance. The project was carried out in accordance with ISO 20252.
2.6 Methods for the in-depth interviews and focus groups

In this section we outline the methods used in the qualitative element of the project. Details of the cognitive study design are provided in a separate report (Gray et al, 2014).

2.6.1 Study areas

The research took place across three geographical areas: London (predominantly Newham and Redbridge), Birmingham and Leeds. These locations were selected to capture variations in socio-economic status and local and regional differences in terms of provision of social care. We identified areas with large Pakistani and Bangladeshi communities using data available from the Office for National Statistics. We deliberately chose two areas with a higher concentration of people of Bangladeshi origin and two with more people of Pakistani origin. The ONS data also provided information about the index of multiple deprivation so we could include locations with a range of socio-economic circumstances. In order to avoid areas which may have been over-researched, we also drew on expertise from the advisory group about suitable study areas.

These study areas were used for all stages of the project: in-depth interview with users, interviews and focus groups with providers and local authorities, and cognitive interviews. The three deliberative workshops were also held in these cities.

2.6.2 Sample

Qualitative research seeks to provide explanations of attitudes or behaviours rather than quantify their prevalence within the population. It is neither necessary nor desirable for qualitative samples to be as large as survey samples or to be statistically representative. Instead, in order to provide robust explanations from which wider inferences can be drawn and to generate conceptual frameworks applicable to the broader population, it is essential that qualitative samples are selected purposively to encompass the range and diversity present in the target population(s). The robustness of qualitative research and the ability to draw wider inference from qualitative studies are highly dependent on rigorous purposive sampling. This is the approach we took for the sampling for in-depth interviews with users and relatives, and for the sample of care providers and local authorities.

Stage 2 sample: In-depth interviews with service users and relatives

The key aim of the in-depth interviews with service users and relative was to explore the experience of accessing and receiving social care. Therefore, the primary sampling criteria for this qualitative work was being in current or recent (within the last 12 months) receipt of local authority funded social care.

The other primary sampling criteria for the stage 2 qualitative sample were:
• Receipt of specific types of care including: home (domiciliary) care arranged by the local authority or through a personal budget or direct payment, day opportunities services, or meals on wheels services and equipment.
• Participants were of Pakistani, Bangladeshi or white British origin.
• Service users lived in the community and not in a residential setting or another institution.
• Demographic information: the sample was selected to ensure representation of both men and women and different ages (18 to 59 years or 60 years and over).

Information on health condition and service type was collected during screening but these were not used as criteria for participant selection. Our initial sampling criteria included specific local authority areas (Newham, Redbridge, Birmingham and Leeds), however this was later relaxed to include other areas within London.

The final sample matrix of 61 achieved interviews is provided in Table 2.1.

<table>
<thead>
<tr>
<th>Table 2.1 Stage 2, Achieved sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sample characteristics</strong></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>18-59</td>
</tr>
<tr>
<td>60+</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
</tr>
<tr>
<td>Bangladeshi</td>
</tr>
<tr>
<td>Pakistani</td>
</tr>
<tr>
<td>White British</td>
</tr>
<tr>
<td><strong>Region</strong></td>
</tr>
<tr>
<td>Birmingham</td>
</tr>
<tr>
<td>Leeds</td>
</tr>
<tr>
<td>London</td>
</tr>
<tr>
<td><strong>Interview type</strong></td>
</tr>
<tr>
<td>Service user</td>
</tr>
<tr>
<td>Relative</td>
</tr>
<tr>
<td>Both</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
</tr>
</tbody>
</table>
Stage 4 sample: Focus groups and in-depth interviews with social care providers

The key aim of the focus groups and in-depth interviews with social care providers was to explore the experience of providing social care to diverse communities. Therefore, the primary sampling criteria for this qualitative work was having a job role that involved managing or providing adult social care, as an employee for a local authority or private care provider organisation.

The specific sampling criteria for the stage 4 qualitative sample were:

- Local Authority senior managers within adult social care
- Local Authority Human Resources Managers, with responsibility for diversity within adult social care services
- Local Authority social workers working within adult social care
- Day centre managers – working for an South Asian specific service or with experience of working with ethnically diverse clients
- Home care managers – working for an South Asian specific service or with experience of working with ethnically diverse clients
- Home care workers providing domiciliary care, with some experience of working with Pakistani and Bangladeshi groups
- Demographic information: the sample was selected to ensure representation of both men and women and different seniority and experience of the role. For care workers ethnic representation was sought across white British or white other, South Asian and Black African or Caribbean backgrounds.

The final sample included 24 participants. We conducted two focus groups with care workers (one with Black African and Caribbean workers and one with South Asian and Muslim care workers) and one focus group with social workers. We conducted seven individual interviews with local authority and provider organization managers. Table 2.2 shows the number of participants included by job role.
### Table 2.2 Stage 4, Achieved sample

<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>LA senior manager</td>
<td>2</td>
</tr>
<tr>
<td>LA Human Resources Manager</td>
<td>1</td>
</tr>
<tr>
<td>Social Worker</td>
<td>6</td>
</tr>
<tr>
<td>Day centre manager</td>
<td>2</td>
</tr>
<tr>
<td>Home Care Manager</td>
<td>2</td>
</tr>
<tr>
<td>Care workers</td>
<td>11</td>
</tr>
</tbody>
</table>

#### 2.6.3 Recruitment

It should be noted here that the recruitment for this project was extremely challenging. The factors which contributed to this included: budget cuts and time pressures on local authorities and organisations which we approached to help us with recruitment, the isolation experienced by members of our target population, and challenges in ensuring appropriate language and gender matching, where required. During recruitment compromises in relation to some criteria (such as area) and final numbers interviewed had to be made.

#### Stage 2: In-depth interviews with service users and relatives

To recruit the stage 2 sample, contact was made with community and voluntary organisations in the three geographic areas. Community and voluntary organisations were indentified by desk-based internet searches and initial contact was made by telephone with service managers to discuss the research and potential recruitment via their service. After this phone discussion, if organisations agreed we sent an email providing information about what participation in this part of the study would involve. We explained the purpose of the research and the content of the in-depth interviews. We included details about what participants could expect in terms of anonymity and confidentiality and offered participants £20 as a token of appreciation for taking part. In addition to this we explained that we could offer organisations, which recruited three or more participants, £75 as partial compensation of the time and cost involved. A follow-up call was made up to a week later. The research team offered face-to-face visits to services to speak directly with management and service users.

Screening of potential participants was conducted by the research team over the phone or in person. Verbal consent was always sought from the service user or relative (where necessary) during recruitment and then again prior to the interview.
Two recruitment agencies supplemented our in-house recruitment of service users and families. They were provided with appropriate recruitment materials and detailed guidance on appropriate recruitment methods which were in line with our ethical approval. One agency was a general research recruitment agency, the other specialised in recruitment and interviews with BME groups.

It should be noted that the recruitment for this project was extremely challenging and multiple approaches had to be used over an extended fieldwork period in order to achieve the interviews. It was also found that a standard recruitment agency had difficulties recruiting for this very specific population of care users from specific ethnic groups.

The research was made as accessible as possible. Interviews were carried out in a venue of the respondent’s choice, and breaks were offered during the interview as required. Interviews generally lasted 1-1.5 hours, and were carried out by members of the research team or specialist bilingual qualitative researchers. Interviews were offered in English, Urdu, Punjabi, Bengali and Sylheti. Wherever possible the interview was carried out with the service user. In cases where the service user was unable to take part in a qualitative interview (due to their health condition or cognitive ability), a relative interview was conducted. In some instances a paired interview took place, with both the service user relative present. During the project the research team applied for ethical amendments to cover this changed design (of conducting relative and paired interviews). The intention had been to conduct two phases of research: interviews with service users and then follow-up interviews with a relative. However after finding that many of the initial service interviews had been conducted with relatives it was decided that the phase of interviewing relatives was not necessary.

The qualitative study participants were asked at the end of the interview whether they would be willing to be contacted about participation in a cognitive interview (Stage 3). See the separate report (Gray et al 2014) for details of the sampling and recruitment for the cognitive interviews.

Interviews with service users and relatives took place between July 2012 and May 2013; by a team of eight researchers in total - four English speaking researchers and four bilingual researchers. All researchers doubled up on early field work to ensure quality across interviews. Early transcription checks were also carried out. The sample resulting from recruitment was also validated.

Stage 4: Focus groups and in-depth interviews with social care providers and local authorities

Several approaches were employed to recruit the stage 4 sample. Local Authority (LA) Senior Managers were identified via council websites searches. The initial approach was an email outlining the research and a request for participation in an interview. A follow-up
A telephone call was made up to a week later to establish interest and arrange a suitable time and date for interview.

LA Senior Managers were also asked to nominate a relevant LA Human Resources or Diversity Lead. The same approach was then followed: an initial email and a follow-up telephone call. Similarly, a LA Senior Manager emailed all social workers within their local authority about the research and invited them to register their interest directly with the research team. Participants were also snowballed through social workers who had registered to take part.

Home care providers and day care managers were contact by an LA Manager and were asked to contact the research team directly if interested. The research team also re-contacted organisations which had supported recruitment at Stage 2; contact was made by email initially, followed by a telephone call.

Care workers were recruited via homecare provider organisations. Recruitment was done through organisations that we had worked with at earlier stages of the project. New contacts were sought via internet searches, followed by emails and telephone contact. Operation managers informed care workers about the research and asked them to register interest directly with the research team. Participants were also snowballed through care workers who had registered their interest. Within the achieved sample care workers from South Asian and Black African or Caribbean backgrounds were included; however, despite targeted and persistent efforts we were unable to recruit and include care workers from white British or other white ethnic groups. It is unclear why these groups did not express an interest in participating in this study, however it may be that the research seemed less salient to them.

Prior to the focus group or in-depth interview participants were provided with an information leaflet outlining the research background, information about what participation in this part of the study would involve and the coverage of the interview topics. Information about anonymity and confidentiality of participation was also included.

The research was made as accessible as possible. LA senior managers and diversity leads as well as day service and homecare managers had the option of a telephone or face-to-face interview. Interviews were carried out in a venue of the participant’s choice. Interviews, generally, lasted 45 minutes- 1 hour, and were all carried out by members of the research team. Social workers and care workers took part in focus groups. Groups generally lasted 1.5 hours, and were all carried out by members of the research team.

Apart from senior manager and diversity leads, participants were offered £20 as a token of appreciation for taking part, and an additional £10 for travel costs was offered to focus group participants.

Interviews and focus groups for this stage of the research took place between May 2013 and August 2013 and were carried out by a team of five researchers. All researchers
doubled up on early field work to ensure quality across fieldwork. Early transcription checks were also carried out.

2.6.4 Interviews and focus groups

Interviews with service users covered the following topics:

1. Background information - living arrangements, family and friends, health condition, overview of social care needs
2. Accessing social care – the point at which care was needed, decision to request social care, process of contacting local authority, assessment process – what worked well or less well, expectations
3. Receiving care – daily activities and level of assistance needed, levels of formal and informal care being received, method of payment for care and support workers
4. Experience of receiving care – overall experiences of receiving care, what makes for good or poor care
5. Gaps and suggestions – gaps in care, suggestions for improvement.

For the full topic guide for service user interviews please see Appendix A.

Relative interviews had a separate but similar topic guide. Interviews covered the same topics as the service user interview, with questions asked of the relative’s experience rather than speculating about that of the service user’s.

Local authority and care provider staff topic guides covered:

1. Participant background – their professional role;
2. Background to adult social care provision – staff and community demographics, relationship between LA and provider organisations;
3. Care journey – mapping the process from accessing care to receiving care;
4. Meeting diverse needs – services offered, training for staff, quality assurance measures;
5. Views on satisfaction levels amongst different ethnic groups.

2.6.5 Interviewing in other languages

Interviews for service users and relatives were offered in English, Urdu, Punjabi, Bengali and Sylheti. English interviews were carried out by NatCen researchers. Four bilingual freelance researchers were trained and employed by NatCen to carry out interviews in the other languages. We offered language matching between researcher and participant as required. We were unable, however, to exclusively offer gender and language matching. There were challenges in recruiting sufficient men and women with the appropriate language and qualitative research skills. Where gender (and language) matching was not possible, but was desired, an interview was offered with two researchers present, one with the appropriate language skills and the other the appropriate gender.
Topic guides were translated from English into each of the other languages, by the bilingual researchers; in the form of a transliteration.

Recordings of minority language interviews were fully translated and transcribed into English. Urdu and Punjabi interviews were transcribed by the interviewer. The Bengali and Sylheti interviews were transcribed by an external translation company direct from the audio recordings.

2.6.6 Analysis of the data

The interviews were transcribed verbatim and analysed using the Framework method, developed by NatCen. Framework is a qualitative data analysis method, which uses a ‘matrix’ approach to conduct theme and case based analysis. Using Framework, we adopted a comprehensive approach to the data analysis ensuring systematic and consistent treatment of every piece of data collected to ensure reliable and valid interpretation. In carrying out analysis of qualitative data, we ensured that the analytical framework was grounded in the data and not imposed by the research team, and was one which met the study objectives.

2.7 Deliberative Workshops

The final stage of the project was a series of deliberative workshops, a participatory approach that advocates actively involving ‘the public’ in decision-making processes, or in this case to assist in the formulation of recommendations. The aims of the workshops were two-fold: firstly to ensure the findings resonated with delegates’ experiences; and secondly to discuss ways in which to address the emerging findings within policy and local practice in a way that is both practical and sustainable. The aim was to generate some realistic new recommendations which are grounded in the current context of care provision and which are appropriate to the groups of interest.

Workshops were held following the completion of research fieldwork and early analysis of the data. A total of three workshops were held in London, Leeds and Birmingham, in Autumn 2013.

Stakeholders from the field of adult social care were invited including representatives from adult social service departments, care provider organizations, service users and carers. We invited people and organisations involved in the earlier stage of the research to attend and asked them to forward the invitation onto their own networks. In total between 30 and 60 people attended each event. Delegates were predominantly from Local Authority adult social care departments, working for care provider organisations and researchers, and some service users.

Workshops were half day events and free to attend. Each event was chaired by someone outside the research team, who worked in the field of social care and had experience of
putting research into practice. We chose a local authority senior manager who had already been engaged in the research; and two chairs from organisations which focus on linking research and practice: Social Care Institute for Excellence (SCIE) and Research In Practice For Adults (RIPFA). Chairs were briefed about the project and specific aims of the workshops.

The format of the workshops was designed to facilitate the generation of specific recommendations. On the day, findings from the qualitative and cognitive stages of the research were presented to delegates followed by focused discussions about the emerging issues, linked to specific findings. There were four different discussion groups, to ensure key topics were discussed in the available time and to allow delegates to select and contribute to an area they are an expert in or had a particular interest in. The four groups were:

- Accessing social care services
- Receiving social care services
- Gathering and using data on social care
- Service user discussion

The same four discussion topics were covered at each of the three workshops. We adjusted the number of groups according to interest. Groups were limited to 12 or fewer delegates. Each breakout group was facilitated by a member of the research team. Facilitators were briefed and experienced at running focus groups.

The recommendations from the workshops are presented within Chapter 6. Workshop discussions are not included elsewhere in the report.
3 Participant characteristics, care scenarios and the cultural context

This chapter provides an overview of the circumstances of the research participants and the contexts in which service users receive social care. It describes the different living and caring scenarios of service users across the three ethnic groups as well as relevant cultural and religious factors which affected social care uptake and use. The chapter ends by looking at the role of family members, particularly women, in providing care to their relatives.

3.1 Service users and formal care

A total of 61 interviews were conducted with service users and/or their relatives, with a more or less equal split between the three ethnic groups. The sample included adults across a range of ages and a good mix of both men and women. Most service users in the sample were aged 60 and over and required care due to age-related illnesses, however we also included service users aged between 18 and 60, a majority of whom had a long term physical or sensory health condition. Service users, and the relatives of service users, with a mental health condition or learning disability were also included in the research. The sample included service users with multiple and complex needs particularly among the Bangladeshi participants.

Participants who received care from agency care and support workers received support from multiple individuals. However, there were also several cases where the same care and support worker visited the service user’s home up to three times per day. Care worker visits lasted on average 30 minutes; participants felt this did not always allow enough time to have their needs met. There were service users and relatives who hoped to receive increasing amounts of formal care as their health conditions deteriorated. There were issues regarding unmet care needs as their care package had either been reduced or not increased as their needs changed which they attributed to the budget difficulties faced by their local authorities.

The accounts of Pakistani and Bangladeshi participants revealed how the use of ethnic matching between themselves and care workers was widespread. Gender matching was less common but this was not raised as a particular issue by the South Asian participants. This could be explained that by the fact that, although it is a religious requirement that personal care must be carried out by someone of the same gender, bathing and washing was in most cases performed by family members.
Informal care provided by family members was a major component of the care received by Bangladeshi and Pakistani service users. It featured less in the accounts of white British service users, who were more likely to live by themselves and to rely on formal care alone.

### 3.2 Living and care scenarios

The types of care scenarios experienced by service users fell into the seven categories described below. A key distinguishing feature between the scenarios was whether a service user lived with a family or lived alone; and the amount of informal care they had access to. The seven types were as follows, more detail about each is provided in the following section:

1. Living with family and receiving home care from family and care and support workers
2. Living with family and receiving care from family, partially funded by a personal budget
3. Living with family and receiving home care from family supplemented by day services
4. Living with family and receiving home care from care and support workers (not family)
5. Living alone and receiving home care from care and support workers
6. Living alone and receiving home care from family and care and support workers
7. Living alone and receiving no home care from care and support workers

It should be noted that in this section we are describing the participants in our project. Where we comment on how common each scenario is, we are referring to the situation in our sample, not necessarily in the population as a whole. The idea of this section is to provide the context for the analysis which follows.

#### 3.2.1 Service users living with family

**Care from family members and formal home care**

The most common scenario among the Bangladeshi and Pakistani groups was a service user living with his or her family and receiving extensive care from family members, supplemented by formal home care for several hours per week. In many cases, the family members were providing virtually 24-hour care for severely disabled relatives. A modest level of formal home care allowed these family members to rest or leave their home for short periods, which they would not otherwise have been able to do.
Care from family members, partially funded by a personal budget

A small group of service users living with their families was receiving funded care from family members, together with care from the same people funded by a personal budget (and in one case formal care provided by outside care workers). In such cases the direct payments from the personal budget covered only a fraction of the time spent on caring activities.

Home care from family members supplemented by day opportunities services

Some Bangladeshi and Pakistani service users who were living with their families did not receive any formal home care. Some attended day centres and received care from their families while they were at home.

Formal care only

A very small group of service users who were living with their families appeared to receive virtually no care from their families. They relied almost entirely on formal care, which ranged from extremely limited to comprehensive.

3.2.2 Service user living alone

Formal home care only

It was common within the white British group for the service user to live alone and rely entirely on formal home care, especially if the service user was older or had mental health problems. Some of these service users had relatives who visited them and helped them in various ways but did not provide social care. Others had no immediate family or no contact with their family. This was also the situation for a small group of Pakistani service users.

Receiving care from family and formal home care

Some white British and Pakistani service users who lived alone received a mix of care from relatives and formal home care services.

Receiving no formal home care

There were two instances of people living alone who received no formal care at the time of interview, but wanted to access formal care.
3.3 Cultural and religious background

Services users’ cultural background and related care needs were expressed, interpreted, and operationalised at three different levels: the service user’s practices and values, the family members’ cultural expectations, and the care provider’s understanding of cultural influences. The care provider could have a good understanding, or could have some misplaced assumptions or stereotyping (see also Croot, 2012; Galdas et al, 2012). The cultural preferences of family members sometimes differed from those of the service user themselves.

Service users taking part in this study emphasised the importance of their cultural background. However there were variations in adherence to cultural based practices and expectations of how cultural factors should impact on the nature of care received. These variations were related to factors such as the influence of family members, socio-economic status and levels of education. Differences were also apparent between those service users who had recently migrated and those who were born in the UK or had lived here for a significant proportion of their life.

Religion played an important role for some service users. Some service users interpreted ill health as their fate or the will of God. In some instances, this view was expressed by service users of Bangladeshi and Pakistani origin who used Islamic religious references to explain their situation of needing and receiving care. This view was more predominant among service users aged 60 and over.

‘I think a lot of Muslims especially put it [ill health] down to God. God wanted it, [so] we will do it. They will suffer in silence. Whereas there is help out here, but parents and their generation, they take it for granted that God has given it [ailment or suffering] and they just take it and they’ve got to live with it’

(Relative of a male service user, Pakistani origin, London)

In many instances, the perception of ill health as divinely determined provided comfort and any support received was similarly attributed. Services users and their relatives who held this belief were not fatalistic, however, and had sought service support; religious belief in fate helped them to feel content with their situation and grateful for any support they received (see Mir and Sheikh 2010):

‘We all say praise be to Allah, we really thank Allah that we are getting this support.’

(Relative of a male service user, Pakistani origin, London)

Among Pakistani and Bangladeshi service users and their families an additional cultural factor was speaking no English or limited English which affected people’s ability to access care or communicate with care workers. This is discussed in detail in the following chapters (see sections 4.2.2 and 5.1.4)
3.4 Resistance to accessing social care

Running throughout the research was a theme that Bangladeshi and Pakistani people with social care needs and their families were less willing than white British people to seek social care. There are a number of cultural factors which may contribute to this which are discussed below. Other more practical factors such as being unaware of entitlements to care, or the difficulty in negotiating care with the local authority are covered in the following chapter. There is also the issue of living arrangements affecting the amount of care provided by the local authority, which affected Bangladeshi and Pakistani service users (see section 4.3.3). In the following section we focus on cultural issues which affect whether care is sought.

3.4.1 The home as a private space

Generally across ethnic groups, the home constitutes a private, personal space, entry to which is usually by invitation only. This was also the case for service users of Pakistani and Bangladeshi origin who took part in this study. A service user summarised this view:

‘Asian families don’t like people from outside coming into the house, um, carers and you know somebody to come in.’

(Service user, Female, Pakistani origin, Birmingham)

This tension in the care worker–service user relationship was also expressed by white British service users. One participant highlighted the strangeness of the relationship between care worker and service user:

‘It’s a strange relationship to have, to let somebody into your home and literally give them the run of it’

(Service user, female, white British, London)

Among Pakistani and Bangladeshi service users and their families, the stated dislike of ‘outsiders’ may be the result of physical and emotional or psychological intrusion, experienced by service users of all backgrounds, being expressed or explained in cultural terms. In a similar way, Griffith (2008) has argued that culture can be used as an idiom for criticising health services. In some instances, this unwillingness to allow ‘outsiders’ into their home was a barrier to accessing care to which service users were entitled.

3.4.2 ‘Taking care of our own’

The desire to care for one’s own family members without help from external agencies was expressed by some service users of Pakistani and Bangladeshi origin. The family based service user - care provider relationship was underlined by an emphasis on a responsibility to look after and an expectation of being cared for. More prevalent among those aged 60 and over, this type of familial obligation was couched predominantly in cultural terms.
‘In our culture [in Bengali culture], somebody has to…takes the role of a kind of person who looks after somebody, and so I’m looking after my sister and my mum’

(Relative of female service user, Bangladeshi origin London)

This keenly felt responsibility to care for family members was expressed not only in the context of homecare provision but featured in discussions about long-term residential care for parents or older relatives more generally:

‘It’s not culturally, in Asian culture…for people to put their parents in care homes or even, you know, um, nursing homes, we don’t do that…Even our religion says not to…do that.’

(Relative of male service user, Bangladeshi origin London)

These views were reflected in the fact that more Bangladeshi and Pakistani service users than white British service users were living with their families. Bangladeshi and Pakistani service users often appeared to take it for granted that their relatives would care for them at home. It was also apparent that some Bangladeshi and Pakistani service users expected their daughters-in-law to care for them, which was not the case among white British service users.

However, there were tensions within families from all three ethnic groups about who was expected to provide care. This partly reflected differences in expectations between service users and family members of different generations. Service users sometimes wanted their families to provide care and were reluctant to rely on formal care, but this was not necessarily the preference of the family members providing care. Many carers found their role exhausting, especially if they were working or had young children, and this could lead to tensions with service users and other relatives. These tensions were especially evident among Bangladeshi and Pakistani families. They were linked to the perceived duty to care for family members at home (often in cramped conditions) and in particular to the expectation that daughters-in-law should act as informal carers.

In some cases, the strain of informal care caused tensions with other members of the family. A Bangladeshi man hinted that the pressure of helping to care for his mother every day at her home had caused problems for his marriage:

‘Maybe in this country what they [white people] do is, for people like my mum and stuff, is that they might put them in a care home, or some place somewhere, where what you might call their needs [are] being all met, or whatever. … What’s happening here is a mixture of state help and family help coming together, which I believe is the ideal mix. It’s not leaving it just to the state, and I get on with my life. The truth is that like everybody else, there’s, you can get pressures from, if you’re married, you’ve got a relationship, this and that, these cause lots of pressures.’

(Relative of female service user, Bangladeshi origin, London)
The assumption that families should provide care at home was also felt to have potential disadvantages for service users. One Pakistani woman believed that poorly-educated Pakistani men were often warry of allowing female family members to receive formal care. She believed that a ‘taboo’ around residential care among Pakistani families sometimes meant that vulnerable people could feel forced to stay with their families against their wishes:

‘If somebody’s unhappy, taken advantage of, and they say “Okay take me out of there” it’s a taboo for the big family tree.’

(Relative of female service user, Pakistani origin, London)

Sometimes it was impossible to know whether informal carers were content with their role. For instance, an older Pakistani man who was interviewed at a day service said that he had no need for formal home care because he lived with his daughter and her family who did ‘everything’ for him. As another example, a Bangladeshi man and his wife talked about caring for the man’s mother, who was receiving no formal care at the time of the interview. Both said that it was their duty to look after her and gave no indication that they were unhappy about the situation, but it is possible that the woman was less open than she would have been if she had been interviewed separately from her husband.

It should be noted that not all older Asian participants in this study expected family members to care for them. In section 3.5 we discuss the circumstances in which independence was considered more important, or in which service users recognised the burden caring responsibilities could place on their families.

### 3.4.3 Attitudes to seeking professional help

The literature on health care provision among different ethnic groups includes discussion of the stigma attached to seeking help from services (Knifton, 2012 in the context of mental health and Singh, 2012 in the context of diabetes). In this study, South Asian services users’ attitudes to social care were cited by local authority and private providers as being different from those of white British groups. The widely held perception was that a stigma was attached to professional social care because the cultural expectation was that family members would provide care at home:

‘I think within the Asian community, sometimes they don’t ask for that extra help, because it’s very much not seen as the done thing, really … And the ones that then do have a carer coming in … families have said they almost feel as though they’re being watched, or they’re almost labelled.’

(Senior manager, day opportunities provider)

According to care staff, the consequence of this attitude was manifest in a reluctance to seek homecare help but in some cases this was also true for day opportunity services. Providers mentioned that some families were concerned about the cultural appropriateness of activities. There were also examples mentioned by Pakistani
participants backing up this view, such as a Pakistani woman with learning difficulties whose brother-in-law had tried to restrict her use of a day service (apparently because he was concerned about her mixing with men) and wanted her to rely on informal care provided informally at home. One Pakistani woman believed that poorly-educated Pakistani men were often wary of allowing female family members to receive social care services for fear that social workers might ‘corrupt the woman’s mind’ and encourage them to live independently.

3.5 Living alone: Family duty versus independence

Some white British service users did live with their families and receive informal care from them, but none of them or their relatives talked about a duty to care family members at home. In contrast, several white British service users emphasised their desire for independence. In some cases this simply meant being able to do things for themselves – for instance, being able to go out for shopping and to see friends. In some cases it also appeared to mean being able to do things without relying on family members. For instance, an older, partially-sighted white British woman who was living alone said that she was close to her family but did not want to ‘take advantage’ of them and was proud of being ‘independent’:

‘I live on my own, I’ve got three wonderful sons, amazing children and daughters-in-law, and six grandchildren. A wonderful family. Close sisters, brother et cetera. Very fortunate. But at the end of the day I’m on my own because I don’t like to take advantage you know. I’m very independent. It’s getting harder by the day but I’m very independent.’

(Female service user, white British, Leeds)

A white British man with a neurological illness who was living alone described how his daughter used to live with him and act as his sole carer while she was a teenager, until it was agreed with a social worker that he needed formal care so that his daughter could concentrate on her studies. Despite feeling isolated, he had come to the view that it would not be fair on his daughter to be his carer:

‘I think it’s all well and good saying it’s down to family and everybody to care for them but she’s the only daughter I’ve got, the only child I’ve got and she’s got a life of her own and she’s got responsibilities and I think the stress of having to look after me as well would tell.’

(Male service user, white British, London)

Although white British service users appeared to place a higher value on independence (including independence from their families) than Bangladeshi and Pakistani service users, the ethnic divide in values was not absolute. There were white British service users who lived with their families and received extensive informal care from them, just as there were Bangladeshi and Pakistani service users who lived alone and received no informal care. Some white British service users bemoaned their families’ lack of interest in caring for
them, while some Bangladeshi and Pakistani service users were keenly aware of the toll which informal caring could take on relatives. For instance, an older Pakistani described how she had decided to move out of her daughter’s home, partly because she did not want to be a ‘burden’ to her daughter and her family:

‘I stayed with my daughter for one and half years and then they gave me a flat. I saw that people can live alone in this country so I requested that I wanted to stay alone too if I can get a flat. I can’t stay with them [daughters family]. What is the point of giving other people difficulties?’

(Female service user, Pakistani origin, London)

3.6 Family Carers

3.6.1 Female carers

Within all three ethnic groups, the main family carers were nearly always women. There were examples of older men being cared for by wives or daughters and older women being cared for by daughters. Within the Pakistani and Bangladeshi groups, it was also common for older men and women to be cared for by their daughters-in-law. In some cases there were other people in the household who helped, but it was more common for a daughter or daughter-on-law than a son to be the main carer. Within the Bangladeshi and Pakistani groups there were several examples of women providing extensive care for adult children with severe health problems. In many cases these women had provided full-time care for many years and had only recently been arranged formal home care to supplement this. These women typically were not fluent in English.

There was evidence to suggest that female carers were struggling with the demands of providing social care to a relative. There were several cases of tensions involving the daughters-in-law of service users. A Bangladeshi woman who was acting as the sole carer for her mother-in-law acknowledged that she found it hard to bathe her and that it would be helpful to have someone else to help. She had not told anyone that she needed more help and did not know how to request further assistance.

‘I have not told this to anyone. … No, whom should I tell? I really don’t know. … It would be better if I could get some help for that purpose. It would be good if they could provide with some help. I shall also do the job if they don’t give the support. What can I do?’

(Relative of female service user, Bangladeshi origin, London)

A Bangladeshi man admitted that his wife was ‘fed up’ with carrying out personal care for his mother:

‘I am the son of my mother. I am doing the help with a smiling face. Nowadays, my wife is fed up with the work. Sometimes, my mother urinates and does the toilet on
the bed or on the floor. My mother needs a female help. I cannot do everything like changing her clothes. My wife does that. The carer does not come all the time. Carers don’t do that. They said that they don’t have regulation to do that. As a result, there is a stress.’

(Relative of female service user, Bangladeshi origin, London)

An additional problem was that, though they may have had the main responsibility for providing care, women were sometimes not the main contact with local authorities and providers. Our research identified a group of ‘hidden carers’. Providers believed that in some instances male family members attended meetings with local authorities and provider managers; resulting in female family members’ views (and that of the main informal carer) not being heard. Social workers, expressed concern about their experiences or being unable to speak to the women providing informal care:

‘We find that sometimes when we go to the assessment it’s the son that’s sitting there, but he’s not the one that’s providing the care – it’s his wife. … And you have to keep saying to him, “Can I speak to your wife?” And he’d be going, “Well, she can’t speak English.” … And you’re thinking – well, I’m female, I’ll go across and talk to her – but they don’t like that. … “Oh, she’s busy now because she’s gone to collect the kids from school.’

(Social worker)

The reason for this could be two fold. It could be true that women providing informal care may not be sufficiently fluent in English to communicate with social workers or care providers or language barriers could be used to maintain traditional social and spatial boundaries between men and women which dictate that men hold responsibility for ‘outward facing’ or public communications. Female care givers did not comment that they were prevented from interacting with providers or the local authority, however it was clear that some would have liked more help but did not know how to go about obtaining it; contact with the local authority or providers could have assisted with this.

3.6.2 Male carers

Although women provided the vast majority of informal care, there were some men within all three ethnic groups who acted as the main carer for a parent, spouse or partner. It is notable that in many of these cases there were no female relatives available to provide the care. If there had been it is possible that some of these men may have been less likely to take on the main caring role, although this was not explicitly stated. An example of this was a Pakistani man who was living for and caring for his blind mother. His wife had recently moved out of the house because of arguments about caring for her mother-in-law, and his only sister was living in Pakistan.

Another Pakistani man described how he and his wife had had to provide full-time informal care for his mother, who was unwilling to have professional carers because ‘she doesn’t really trust other people’. When he tried to get formal care this was refused by the local
authority – because his mother had previously turned it down, he suspected – and as a result his marriage had broken down:

‘It has led to a family breaking up because nobody was willing to provide that help.’

(Relative of female service user, Pakistani origin, Leeds)
4 Accessing care and relationships with local authorities

This chapter explores service users’ and their relatives’ experiences of accessing care and their relationships with local authority adult social care services departments. It describes their understanding of the social care system, interactions with local authorities, views of their local authority care package, relationships with social workers, and their experiences of personal budgets and direct payments. Local authority and provider perspectives on these topics are also included. The chapter ends by looking at communications between local authorities and care providers.

4.1 Confusion about adult social care services

Service users and relatives across all three ethnic groups were often confused about the organisation of adult social care services. Many were not sure whether the services they received were provided by their local authority, the NHS, another public body or a charity. In some cases, services were said to be provided by ‘the government’ or ‘the office’. Concepts such as personal budgets and direct payments were unfamiliar to many people, and were sometimes confused with welfare benefits. The interviews also revealed uncertainty about the organisations involved in delivering social care and related services, and about the different roles of social workers, occupational therapists, carers and nurses.

Although people from all groups found the social care system confusing, Bangladeshi and Pakistani families found it particularly bewildering, and felt that this put them at a disadvantage.

4.2 Service users’ interactions with local authorities

4.2.1 Finding out about adult social care services

Service users and relatives from all three groups often said that they had known little or nothing about adult social care services until a third party, such as a neighbour, community worker or doctor, suggested that they get help. Some families had struggled for months or years without any form of social care and had not thought of contacting the local authority. Others had used one type of service (such as a day opportunities service) and had not known that other services (such as home care or home adaptations) might be available.

Whilst white British participants described how they were unsure about whether they would be entitled to received local authority assistance or how to find out about services
available; Bangladeshi and Pakistani families were especially likely to say that in the past they had not known about the existence of adult social care services at all. In some cases they had only recently accessed services despite having had critical needs for many years. For instance, the Pakistani mother of a severely disabled woman said that the family had only received social care services for the past three years, after a friend with a disabled son raised the subject and urged her to contact a centre for people with learning difficulties. Until then, she had not known about adult social care services, even though her daughter had attended a special school and received medical attention for multiple physical and mental health problems. Another Pakistani woman with a disabled daughter believed that there were many people like her in a similar situation:

‘We remain last in the queue for everything because we don’t even get to know about our rights, what we are entitled to’

(Relative of female service user, Pakistani, London)

As discussed in more detail in section 4.2, according to Bangladeshi and Pakistani families, part of the reason for this lack of awareness was a feeling among Asian families that it was their responsibility to look after disabled family members – an echo of previous findings on poor uptake of medical services (Hussain, 2006; Hanley, 2007; Austin et al., 2009; Wells and Wagg, 2007). This made some of them reluctant to ask the authorities for help or even to discuss their needs with people outside the family:

‘I mean as, as [someone from an] Asian background, I think a lot of people feel that, that is their duty to look after their son and daughter, especially if they have disabilities, and they don’t feel that other people are there to contribute something towards it.’

(Relative of female service user, Pakistani origin, London)

Other perceived barriers to accessing services related to language and education. Families in which nobody spoke fluent English said that they had found it hard to get information about what social care services were available, and had often had to rely on neighbours or others as intermediaries. For families with no fluent English speakers or a low level of education, the paperwork involved in accessing care was daunting. Even for those who had succeeded in accessing care, these barriers often remained:

‘Actually we have no idea what to do, what not to do, where to go, where not to go, where to get help from, where not to get help from’

(Relative of male service user, Pakistani origin, London)

Not all Bangladeshi and Pakistani families faced these barriers; negotiating the social care system was much easier for people who were highly educated, fluent in English and knowledgeable about the system. For instance, a Bangladeshi retired professional (who spoke fluent English) had managed to obtain care relatively quickly, as had a Pakistani woman whose daughter-in-law was a social worker and had helped to arrange an
assessment. If there was nobody within the service user’s family with these attributes, it helped to have a professional, such as a day opportunities manager, to assist service users and relatives by providing information about local authority services and to help initiate contact with the local authority adult social services department.

Local authority staff and providers understood the need to raise awareness of services among these communities. They believed that circulating written information about social care services was not the best means of raising awareness among South Asian groups, particularly older people, because some of them could not read English or any other language. Word-of-mouth approaches were felt to be more effective for this group.

Local authority staff discussed the importance of targeted outreach work in order to engage with their South Asian communities, and raise awareness about available services. One senior manager in one local authority outlined a pilot scheme called ‘community navigators’, whereby bilingual staff based in day opportunities services with a good knowledge of local communities and local authority services, helped refer people to appropriate services. The local authority was planning to review the pilot after six months before rolling it out across the city. Another manager described how his local authority funded a specialist community organisation to provide support to people needing social care services. This service offered information on a range of social care topics, including direct payments and recruiting care workers.

Among the female informal carers from Bangladeshi and Pakistani backgrounds, we interviewed those could be described as ‘hidden carers’, in that they had multiple or very demanding caring and household responsibilities and were not in contact with many (or in some cases any) formal services at all (see section 3.6.1 for more discussion on female carers). Some service users too were isolated and not in touch with many formal services. In addition, there were a number of individuals who were not eligible to participate in this research but wished to; although they did have social care needs they were not in receipt of local authority funded care, and therefore were not eligible to participate. It is a challenge for local authorities to engage with such carers and service users.

4.2.2 Communicating with adult social care services departments

There were families among all three ethnic groups, including some who did not speak fluent English, who had found their local authority social care department efficient and straightforward to work with. For instance, one Pakistani man said that the local authority had contacted him soon after he registered his wife as blind and had arranged an assessment within two months. This was followed by an offer of a place at a day opportunities service and, subsequently, by increasing levels of home care.

Other families had had experiences of poor communications by local authority social care departments. It was widely felt that social care departments (and social workers in particular) were hard to reach by telephone. Dissatisfaction was related to local authorities not returning calls, or not following up on phone calls made and not proactively being in
contact with service users. Departments were said to be bad at providing basic information to families, for instance, a Bangladeshi man said that he was not given the contact details of the manager of his brother’s care home or a copy of his care plan\(^1\).

Local authority staff acknowledged that it could be difficult for some groups of people to contact the adult social care services department. They linked this to a recent shift among local authorities away from face-to-face communications towards telephone contact centres. A group of social workers at one local authority expressed concerns about the closure of all walk-in centres. Service users and their families now had to use an automated telephone system to contact the adult social care services department, which created problems for people who were not fluent in English or were using pay-as-you-go mobile phones. If service users preferred to visit local authority offices they had to stand in the public reception area and discuss their problems there.

Although telephone contact centres had procedures in place to take calls in languages other than English, the systems they used were said to be haphazard. For instance, one local authority had a three-way interpreting service, but interpreters with certain dialects were not always available. Staff in another local authority sometimes found themselves searching the office for a colleague who could speak the caller’s language. Initial messages on the automated telephone system were in English, and callers sometimes hung up before they could be transferred to someone who spoke their language.

### 4.2.3 Accessing services

According to families from all three ethnic groups, local authority social care departments were not felt to be proactive in providing support and assistance. This tended to be put down to a lack of resources rather than deliberate obstructiveness. The result was that it could be hard to get an assessment and could take many months for services to be introduced or increased. Many families felt they had to be extremely persistent to obtain the care they needed. Some had gone to great lengths to obtain their current care packages; for example, a white British service user (who had worked as a health professional before becoming unwell) had made complaints, engaged a solicitor and appealed until he received his current level of care. It was widely agreed that families needed to work hard for services by chasing and challenging local authority social care departments:

> ‘Those that don’t ask don’t get anything’
> (Female service user, Pakistani origin, Leeds)

Bangladeshi and Pakistani families felt that they needed to ‘fight’ for services and the paperwork involved in challenging decisions put them at a disadvantage compared with

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\(^1\) This participant had been caring for his brother at home (including receiving formal care at home) in the previous 12 months which is why he was included in the study, although his brother was now receiving residential care.
white British families, largely because of language barriers. For instance, a Bangladeshi man said that it had taken seven years to get his brother referred to a Bengali care agency and that one of the reasons for this was that his family had not known how to make a complaint. He had since learned how to put a complaint in writing whenever any public body turned down a request. This example also illustrates the value of knowing, or being able to learn about, local authority processes when navigating the social care system. Although white British service users often said that they had had no knowledge of the system when they first applied for care, it may be that because of their fluency in English they were in a better position to grasp these processes.

Some Bangladeshi and Pakistani families were at a loss as to how to challenge local authority decisions. For instance, a socially isolated Pakistani woman with a sensory impairment who attended a day opportunities service wanted home help, which her local authority had refused. She knew that other people at the centre had been granted home help but had no idea what she could do to access this type of help.

Local authority managers discussed how budget cuts had reduced the range of the services they could offer. Provider staff also expressed concerns that budget cuts had reduced the quality and range of the services local authorities commission. For instance, a senior manager at a day centre provider said that the organisation had had to abandon its 18-year-old meals-on-wheels service (providing halal and Indian vegetarian food) after the local authority cut its subsidy. There was no suggestion that services targeted at Bangladeshi and Pakistani groups were disproportionately affected by budget cuts, but the cuts may have heightened the need for all service users and their families to ‘fight’ for adult social care services; a task which Bangladeshi and Pakistani groups found particularly difficult.

Local authority and provider staff believed that Bangladeshi and Pakistani service users who did not speak English were at a disadvantage when arguing their case. For this reason, a senior manager of a day opportunities service said that their staff helped service users who did not speak English and struggled to communicate with the local authority (‘because they can’t speak the language they’re not listened to’) by advocating for them and liaising with the social care services department on their behalf.

4.3 Service users’ views of what local authorities offered them

4.3.1 Service users’ expectations of adult social care services

Despite the problems which many families had faced in their dealings with local authority social care departments, they often expressed gratitude that the services existed at all. Service users and their relatives talked about the huge difference which social care, especially home care and day-care centres, had made to their lives, and some said that
they would not be able to cope without it. Those who were particularly positive included Bangladeshi and Pakistani service users, saying that they had had no expectation of receiving care and were grateful to the local authority or ‘the government’ for providing it at all:

> ‘Some people say that you could possibly ask for more, but the truth is when you come from zero to what I get I’m very grateful. Plus maybe my background being Asian and not being born here and stuff, I’m very grateful’

(Relative of female service user, Bangladeshi origin, London)

The quote above could indicate a feeling on the part of the service user’s son that, as immigrants, the family were not fully entitled to social care services. In contrast, a Pakistan woman whose disabled husband was receiving formal home care made it very clear that she did not feel this way. She said that she was grateful for the care provided by the British government because ‘nobody in Pakistan gets any help’, but said that her husband had worked and paid tax in Britain for many years so it was fair that the government should provide support:

> ‘Nobody in Pakistan gets any help. The government here looks after us and this is more than enough. This is a big deal too and I am really grateful to Allah. [My husband] has worked all his life, always paid taxes in full. We have never taken any kind of support … so then it is his right that he gets some support now that he needs it.’

(Relative of male service user, Pakistani origin, London)

Although this woman was adamant that her husband was entitled to care, her comments also contain an implication that he might not have had the same entitlement if he had not worked and paid tax in the UK. It is not clear whether this perception was shared by other Bangladeshi and Pakistani families, and if so, how it may have affected their satisfaction with social care services.

In contrast, two families of Pakistani origin had been disappointed at being refused a care worker to accompany them on trips to Pakistan or Mecca, an unrealistic expectation, which may have been caused by language problems and confusion about the meaning of respite care. These cases highlight how having a poor understanding of local authority services can affect people’s expectations. It also demonstrates how misunderstanding of the remit of local authority support services could lead to a perception that they are insensitive to people’s cultural needs.
4.3.2 Unmet care needs

Within all three ethnic groups, there were reports of unmet care needs, and a need to increase the number of formal caring hours. There was dissatisfaction among service users and relatives from all three ethnic groups over the level of care which local authorities were willing to fund. Nearly all participants would like to receive more hours of formal care, but underlying this were varying types of unmet need. We identified six main types of unmet need:

- The service user is not getting as much care or time as they need (e.g. only having a shower once a week or being rushed on the toilet)
- Care needs are being met at present, but only because of the input of family members who need more support or respite in order to continue.
- Care needs are being met at present by family members but the service user would prefer that the care is provided by a care and support worker, but the family do not want this.
- Care needs are being met by family members who received a personal budget, but the personal budget only covers a small amount of the care being provided.
- Equipment is needed but has not been provided at all, or an alternative which does not meet service user needs has been provided.
- The service user is lonely or lacks social contact and this need is not being met in their current care provision.

Unmet need for home care (first four types of unmet need) was raised by Bangladesh and Pakistani families more than white British families. It may be partly because the interviews with Bangladeshi and Pakistani families were often conducted with family members caring for disabled relatives, whereas the interviews with white British families tended to be with the service users themselves.

The small group of service users living with their families who were receiving care funded by a personal budget from family members belonged to the Bangladeshi and white British groups. In some cases the carer lived with the service user. In one of these instances it was said to have been a struggle to arrange this, because of the presumption against providing personal budgets to people living with the service user, which may explain why there were few relatives receiving personal budgets within the Bangladeshi and Pakistani groups despite the high levels of family care within these groups. Another factor is that there was a view that local authorities were reluctant to provide a high level of formal care to service users living with their families, and that because Asian service users often lived with their families they received a lower level of formal care than people from other ethnic groups. This is discussed more in section 4.3.3.

Several families reported that their home care had been reduced because of budget cuts, and some feared that their care might be stopped altogether. One white British family was upset at being refused extra homecare on the grounds that they could afford to pay for it
themselves. Another was unhappy about the shift from local-authority care towards private-sector agencies which were perceived as being understaffed and providing a worse service.

Service users and relatives from all three ethnic groups were disappointed that their local authority had refused to carry out home adaptations such as installing a walk-in shower, a downstairs bathroom or a stair lift. Other reported causes for dissatisfaction included poor-quality meals on wheels, lack of help with transport, and a desire for better-quality day services.

One of the greatest unmet needs was lack of social contact, particularly for service users who lived alone, or Pakistani and Bangladeshi service users and relatives who had little contact with extended family networks. Isolation and lack of companionship had an impact on people’s wellbeing. Those with little other social contact placed greater importance on any formal social care being received.

‘There are people [professional care workers] that really take care of me here and may Allah bless them and the biggest problem is the loneliness, it is killing me. My daughter-in-law says come and stay with me but she is busy with her life, taking her children to school, picking them up, going shopping.’

(Female service user, Pakistani origin, London)

Homecare managers too, noted how there are no formal funding sources for companionship. Managers felt social contact to be an important aspect of service users' health and wellbeing; and believed regular social contact could be a preventative therapy.

‘Companionship is one of those areas which is vastly overlooked...there’s no program to engage with companionship because nobody recognises it as a necessary therapy. If you need personal care that’s fine, people will fund that. If you need some cleaning, people will fund that. But if you just need a friend, oh no we don’t do friends, sorry. ...It’s a valuable therapy, if somebody makes you smile it can cheer up your whole day and give you a reason to look forward to tomorrow.’

(Home care, senior manager)
4.3.3 Perceived discrimination

Service users and relatives from all three ethnic groups did not suggest that local authorities discriminated directly against certain groups when deciding whether to provide social care services. However, there was a view that local authorities were reluctant to provide a high level of formal care to service users living with their families, and that because Asian service users often lived with their families they received a lower level of formal care than people from other ethnic groups:

‘If they know they have an Asian, Bangladeshi or Pakistani person they will already know that they will have someone looking after them. They will turn a blind eye. This is a big, big issue whereas if they know a white individual or a black individual they will think they are alone – and they will be alone.’

(Relative of male service user, Pakistani origin, London)

The perception of unfairness implied in this comment highlights two conflicting views about entitlement to formal social care. One view is that people who are living alone and do not receive care from family members may need a higher level of formal care. The other is that it is unfair for local authorities to take account of care from family members when deciding on the level of formal care because this discriminates against certain communities. There was no evidence that local authorities had made misplaced assumptions that Asians were living with their families when they were not. Nonetheless there was evidence of pressure on the individuals in the family responsible for providing the care.

One person, who had been refused a personal budget for his live-in partner to act as his carer, felt that local authorities discriminated against white British service users. He believed that the payments might have been granted if he had been Muslim and married, and had said to the social worker that he did not want anyone except his wife to touch him.

Local authority and provider staff did not express the view that local authorities discriminated against certain groups when deciding whether to offer services. However, there was a view that the types of services on offer were inadequate for some ethnic groups. For instance, a senior manager at a home care provider felt that their local authority had a poor understanding of black and minority ethnic service users’ needs. A senior manager in that local authority acknowledged that its services were perceived as ‘very white’ and contrasted the strong provision in the area for Jewish service users with the lack of provision for more recent migrants. Talking about day opportunity services he acknowledged that:

‘I think that [our] services feel very, very white and I think that can be a difficult thing. I think it must be very hard being the one, or one of two, people in a service of 50 or 100 people.’

(Senior manager, local authority)
One local authority manager said that the authority tried to make sure that all of its social care provision was acceptable to all communities, while at the same time it commissioned a small number of services for specific groups. These services had developed gradually over time. There was currently no strategy for social care provision targeted to different ethnic groups, but this was something which the local authority was considering. The manager believed that, despite not having a strategy in place, the social care services department understood the needs of different groups because it had a diverse workforce which reflected the population it served.

Another local authority manager believed that the authority’s policy of ‘micro-tendering’ (inviting providers to tender for individual care contracts) had pushed up quality and provided more choice, especially for service users from BME groups seeking culturally-sensitive care. The same manager warned that the approach also had some risks, because it was attracting new providers which the local authority knew very little about.

4.3.4 Perceived differences between local authorities

There was no evidence to suggest any differences in service user and relative satisfaction or experience of social care services across the local authorities included in the research. However, families who had moved from one local authority area to another, or who had relatives living in another area, talked about differences in provision between local authorities. For instance, one service user contrasted the ‘abysmal’ care he had received from his previous local authority with the ‘absolutely brilliant’ care he was currently receiving.

4.4 Relationships between service users and social workers

4.4.1 Good relationships

Among all three ethnic groups there were service users and relatives who spoke positively about their social workers. The best social workers were described as being sensitive to the needs of the family, knowledgeable about the social care system, efficient, good at keeping in touch, and easy to contact. In particular Bangladeshi and Pakistani relatives liked it when social workers took into account the families needs as well as those of the service user.

Bangladeshi and Pakistani families in which no adults spoke fluent English did not necessarily expect their social worker to speak their language. Some spoke highly of their social worker, with whom they communicated through an interpreter or an English-speaking family member. Shortcomings of the social care system were not always blamed on individual social workers. For instance, a Bangladeshi man who was highly critical of the care which his relative had received in the past said that he had come across
energetic and enthusiastic social workers who wanted the best for their clients but were blocked by their managers because of budget restrictions.

4.4.2 Poor relationships

Families from all three ethnic groups described negative experiences with social workers. One of the main complaints concerned social workers who seemed willing to help but did nothing and were never seen again following an initial meeting:

‘They write and they leave and they don’t come back ... The social worker now is ok. The one before used to speak nicely and say nice things but never did anything.’

(Relative of male service user, Bangladeshi origin, Birmingham)

Examples were given of social workers who missed appointments without explanation, did not return calls, and, in one case, lost their notes on a client.

Although language barriers between social workers and their clients were rarely mentioned, there were complaints about social workers who failed to arrange interpreters, and about incompetent interpreters. Social workers believed that it was important to use skilled professional interpreters when dealing with service users and families who did not speak fluent English, even though this could be time-consuming to arrange. It was said to be poor practice to use family members as interpreters because of the risk that they might interpret selectively or inaccurately, for instance, if they were wary of a care package being recommended by a social worker because it required a financial contribution from the family. Social workers pointed out that it was not always enough for interpreters to share the same language as the service user or family members, sometimes they needed to be able to speak a particular dialect.

It was acknowledged by social workers that reviews with Bangladeshi and Pakistani clients were often conducted entirely in English, and that there was not always an interpreter present in cases where the service user or family members had difficulty understanding English, which was one of the problems identified by Merrell et al (2006). One Urdu-speaking social worker said that he knew of a service user who never used an interpreter. He pointed out that if this service user were arrested by the police he would not be interviewed without an interpreter, and suggested that the same standard should apply in social care reviews.

Cultural barriers to good relationships were occasionally mentioned. An older Pakistani woman was upset that her social worker had not arranged for someone to accompany her to a supermarket so that she could donate food to a collection organised by a mosque during Ramadan. Another Pakistani woman said that a social worker had offended her relative, who prepared meals for the service user, by suggesting that a care worker could be arranged to help with cooking. She felt that the social worker did not understand that Asian people do not like ‘people from outside’ going into their homes. She said that the
ethnic background of the social worker did not matter ‘as long as they understand the culture’. These comments point to a need for social workers to be ‘reflexive practitioners’, as argued by Atkin and Chattoo (2007) in relation to health services, and to demonstrate a degree of ‘cultural competence’ (Yeowell, 2010).

Social workers said that they needed to manage clients’ expectations during initial assessments, because the panel making decisions about care provision did not always approve social workers’ requests. Although service users could appeal, the process took time and could make people feel angry and dissatisfied.

### 4.4.3 Continuity among social workers

One of the main criticisms from service users and relatives from all three ethnic groups was the lack of continuity among social workers. Families often said that they saw a different social worker at every assessment, which meant that they had to re-explain the situation each time which made it impossible to build a relationship. Some said that they did not know who their social worker was or that they did not have one:

“We don’t have any specific social worker at the moment. We have to contact the social services team in the area to get hold of the actual social worker.”

(Relative of male service user, Bangladeshi origin, Birmingham)

The importance of a sustained relationship with a competent social worker came across in interviews with families who had contact with a series of unhelpful social workers until they eventually encountered a social worker who listened to them and worked with them until they got the care they needed. The son of an older Bangladeshi woman still remembered the name of the social worker who had arranged care for his mother 17 years earlier:

“[The social workers] were just coming in, just quickly and go, whereas one person who did come, he would go a bit further and he would put himself out, so he’d take Mum to this centre. He took a more proactive approach…all I can say is his attitude was different and he seemed more knowledgeable, and he was willing to push the levers.”

(Relative of female service user, Bangladeshi origin, London)

A group of social workers at one local authority said that budget cuts had led to cases being split between different teams, which made it harder to build long-term relationships with service users.

### 4.5 Personal budgets and direct payments

Service users and their families had mixed feelings about personal budgets (an allowance of money which service users can use to meet their needs, often not through the services usually commissioned by local authorities) and direct payments (where the local authority gives users a sum of money to pay for services themselves or as the way of receiving their
Among all three ethnic groups there were families who were happy to have been able to choose who provides their care, and in particular to have had the option to employ family members using personal budgets. However, some Pakistani service users had found the paperwork associated with direct payments (whether for a personal budget or paying for services) hard to deal with, and some had run up large debts as a result. For instance, a woman of Pakistani origin with learning difficulties had been unaware that she had been running up a small weekly charge to attend a day centre until she was presented with a bill for £2,000 and told that she could no longer attend the centre. The centre manager, who said that this was a common problem, intervened and it was agreed that she could continue to attend if she gradually repaid the charges out of her welfare benefits. Other service users also complained that charges were not always made clear until it was too late. Some wanted nothing to do with direct payments because they thought that they would find them too difficult or stressful to administer.

Local authority and provider staff had mixed views about direct payments. Some felt that they were beneficial as long as service users and their families could cope with the administration. A group of social workers believed that direct payments were particularly valuable for South Asian service users because it made it easier for them to employ care workers from their own ethnic background, including family members:

‘Now you’ve got direct payments coming in, now we don’t have the traditional white person going in [to South Asian households], so you can actually choose somebody from your background who understands you. So it’s getting a bit easier for them [South Asian groups], what I’ve found.’
(Social Worker)

Others pointed out that direct payments could be difficult to operate, particularly for South Asian families who did not always have the documents needed to open bank accounts, such as birth certificates and passports, and sometimes struggled to keep track of invoices and payments. A senior manager at a day opportunities service said that service users could suffer when their families took responsibility for their care, because some families saw personal budgets as an opportunity for additional income and switched service users from local authority-funded day services to family homecare:

‘Once parents have got hold of their own personal budgets, they’ve got withdrawn from the service, and then years later they come back through the system but their deterioration is massive.’
(Senior manager, Day opportunities provider)
4.6 Communications between local authorities and care providers

When referring individuals to private care providers, local authorities were said to give limited information on the person, and the type of information differed from one local authority to another. For example, a generic homecare provider was never informed about an individual’s ethnicity or about any language needs they might have. In contrast, a specialist home care provider, interviewed in a different local authority area, was always provided with ethnicity information and informed about preferred language, but not provided with information about religion. Homecare providers were left to make assumptions based on an individual’s name or to find out during their initial contact with the service user.

Social workers pointed out that the role of local authorities in the provision of care was changing and that increasingly they were working with private providers. However, there was a concern among providers that local authority staff were unaware of the community services available in their borough. One specialist day opportunities service catering for South Asian elders reported problems with social workers not referring suitable individuals to their service as they did not know about it. The day service manager was surprised by this, as it was the only service of its kind in the borough.
5 Receiving Care

This chapter explores service users’ and their relatives’ experiences of receiving social care services, both in home and out-of-home care. It describes their relationships with homecare workers, expectations and markers of quality care. Local authority and provider perspectives on these topics are also included. The chapter ends by looking at day opportunity services, transport, meals on wheels and respite services.

5.1 Relationships within homecare services

5.1.1 Service user and care worker relationship

The relationship between service user and care worker was central to satisfaction with social care, across all three ethnic groups. Care workers were typically an unknown and unrelated person, working closely with the service user, in their home. They provided assistance with day-to-day living, which could include personal care. Some service users had multiple care workers attending to them.

It took time for relationships to be established; multiple visits were required for care workers to learn the care plan and know what they had to do and similarly, it took time for service users to feel comfortable and trust individual care workers, particularly where personal care was being provided. These relationships had to be renegotiated over time, particularly in line with changes in health needs, care workers and family involvement in care provision. Despite such changes there was an aspiration among service users and relatives to maintain continuity in the care they received.

Care workers were expected to be both professional and personable. Completion of required care tasks within the allocated timeslot (i.e. being professional) was not enough to achieve satisfaction. It was also important for care workers to carry out tasks in a caring way, whilst engaging with the service user (i.e. being personable and caring). Being personable helped to establish a human relationship as opposed to a purely professional transaction.

‘I think it’s important that, there [are] three attributes. One is punctuality, two is the rapport and three is getting the work done properly. She’s [my care worker] got all three. If you haven’t got all three, then it might be a problem’

(Service user, male, white British, London)

There were two clear challenges in achieving a satisfactory balance of professional distance and a caring closeness for both service user and care worker. Firstly, there was an issue of expectations. Some service users and relatives had unrealistic expectations of care workers duties, for example, an expectation that care workers could do tasks outside
the agreed care plan. Secondly, care workers had pressurised workloads, resulting in having to rush or struggle to complete all tasks in the given time.

Although there was a desire to have a care worker who was both professional and personable, there was a stronger desire amongst white British participants to have a care worker they liked and could relate to on a personal level (e.g. wanting a ‘chatty’ care worker). Pakistani and Bangladeshi service users and relatives, on the other hand, did mention instances where care workers were personable, however a greater priority seemed to be on having a care worker who performs the tasks needed. This point of difference might be indicative of a difference in view amongst service users compared to relatives; as more white British interviews were done with service users and more relative interviews done with Pakistani and Bangladeshi groups. However it might also be due to a difference in the perceptions and expectations of formal care workers across these ethnic groups.

5.1.2 Consistency of care

Consistency in homecare was a key contributor to satisfaction, across ethnic groups. As with the relationships with social workers described in chapter 3, service users and relatives placed importance on a sustained relationship with a competent care worker. Provider staff, too advocated for arrangements whereby care workers could build a relationship with the service user, to help them understand the service user’s needs and gain their confidence:

‘Regularity [of care worker] builds up continuity and a consistency in the delivery of service. Also builds up trust, understanding and confidence, and brings the customer, who are usually vulnerable, out of their shell, gives them the confidence to be able to speak to their care worker, gives them the confidence to be able to re-engage with tasks and maintain, or even improve, some of their independence.’

(Senior manager, homecare provider)

Changes to care staff, whether permanent or temporary, such as holiday cover, were not always managed well. It was daunting to have a new and unknown care worker. Concerns centred on whether the new care worker would be ‘good’ or ‘nice’. Participants had established strategies to avoid such uncertainties. For example, one relative pushed to have three named care and support workers who were trained to know the service user’s care plan. Though only two were regularly needed, the third care and support worker was employed to cover when needed.

New care and support workers had to re-learn the care plan and the service user – care worker relationship had to be re-established. Furthermore, new staff would not be accustomed to service users’ mannerisms, body language (particularly, where the service user was non-verbal) and behaviours related to their health condition. Having to instruct new care and support workers on the care plan was a point of annoyance, particularly in
cases where there was high staff turnover. These frustrations were compounded when the service user or relative and the care worker did not share a common language.

‘A new girl [care worker] comes and this is what they will say ‘where’s the soap, where’s the toilet, where’s the towel’. This is such a big headache.’

(Relative of female service user, Pakistani origin, London)

5.1.3 The difference between caring and care work

Service users and relatives wanted care workers to have a positive attitude to caring. Service users and relatives described two different types of care workers: those who actually care about the work they do and those who view care work as a job. Having a care worker who cares was desirable.

‘So the ones who really care and the ones who are going through the motions, so it all boils down to the attitude.’

(Relative of male service user, Bengali origin, London)

Service users and relatives liked it when care workers performed tasks outside of the care plan. Such activities included feeding pets, ordering goods for the service user in their lunch breaks, providing support to other people within the household and visiting or taking service users out on their days off. Although performing tasks outside the agreed care plan could be viewed as ‘unprofessional’, it made service users feel important to the care worker and cared for, particularly those who were otherwise socially isolated. One service user described her dissatisfaction at a care worker refusing to perform tasks outside the agreed care plan, such as buy basic groceries.

‘I have had carers who sort of said, 'It’s not my job', and flounced out leaving me without bread and milk at the weekends.’

(Service user, female, white British, London)

It was important that service users liked their care worker. Personal qualities and personalities of care workers contributed to the care worker - service user relationship and overall satisfaction. Service users talked about liking and enjoying the company of their care worker and relatives reported satisfaction when they felt that their relative liked the care worker. For all three ethnic groups, interpersonal skills were as important as practical skills and knowing how to do the job.

Whilst care work is task based, and a source of employment for care workers; service users were reliant on their services, and those who were socially isolated were also reliant on their care worker for regular social interaction, meaning the personal relationships mattered even more.

‘I mean that’s probably the highlight of your day’

(Service user, Male, white British, Leeds)
5.1.4 Communicating with care workers

Having a shared language with care workers enabled service users or relatives to instruct the care worker with ease and aided the establishment of a personal relationship. However, not all Pakistani and Bangladeshi families wanted a care worker who could understand the language spoken in their home.

Not having a shared language with a care worker was experienced across all three ethnic groups. There were cases of white British service users being allocated care workers who spoke limited English. Equally Pakistani and Bangladeshi service users and relatives were inappropriately matched to English speaking care workers or to a South Asian care worker with whom they did not have a shared language. Some people had developed strategies to overcome language barriers. A common strategy was to bring in an English speaking relative when needed, to act as an interpreter.

‘If I don’t understand anything, they [care workers] call my daughter so that she can make me understand.’

(Relative of female service user, Bengali origin, Leeds)

Another approach was acceptance of the language barrier, providing the care was of a good standard and the care worker displayed a positive attitude to caring. Having a positive attitude could bridge language and communication barriers. Where the service user and care worker did not have a shared language or in cases where the service user was non-verbal, the communication gap could be bridged by the care worker being friendly and engaging. For example, one mother explained that care workers sang to her daughter who is non-verbal, and she felt her daughter enjoyed this interaction.

There were also communication difficulties related to an individual’s health conditions, even when they could speak the same language as the care worker. For example, a Pakistani service user who had an English speaking care worker would at times forget how to speak English following a stroke. One white British man found it increasingly difficult to understand care workers for whom English was not their first language, due to his deteriorating hearing. In addition, a number of service users were non-verbal; in such instances, relatives wanted care workers to be mindful of the service user’s body language.

5.1.5 Respect in communication

In most South Asian cultures, the manner and mode of address signifies respect. This is particularly true when addressing older people. One manifestation of ‘respect’ could be to address an older female service user in culturally appropriate terms (with words such as Ammaji (mother) - a respectful word for older women). Following cultural norms, for example, in how service users are addressed, not only denotes respect but is an important
way to personalise care. One mother of a Bengali service user described care workers as being jolly and said they called her ‘mum’, which helped to build rapport despite the lack of a shared language.

When discussing this issue some homecare providers emphasised the importance of maintaining professional boundaries when providing homecare. The view was that that one way of making a distinction between formal, professional care and domestic service was for care workers to address service users by name instead of using affectionate terms such as ‘Auntie’:

‘You can empathise. Don’t sympathise. You will go in as professionals and formalise the care. That’s why you’re coming in the first place. … Don’t say, “Oh, Auntie was crying.” … Straightaway I will refer to them as “Missus Patel, I’m here.” You know, it all starts off with … “Auntie, are you okay?” Already we’ve broken those boundaries.’

(Senior manager, homecare provider)

In contrast, a senior manager at a day service for older South Asian people was proud of the fact that their staff addressed service users as ‘Uncle’ and ‘Auntie’, which she felt made the day centre ‘family oriented’:

‘We don’t refer to them with names. It’s like “Uncle” or “Auntie” and they refer back to us the same – “My daughter” or “Sister” – and so it just gets really family oriented.’

(Senior manager, day opportunities provider)

This positive view of affectionate terms such as ‘Auntie’ should be understood in the context of day care, where the boundary between professional care and domestic service is not an issue.

5.1.6 Working together: formal home care provision alongside family care

Pakistani and Bangladeshi relatives described their general satisfaction with having any formal care provision at all; particularly when care provision had predominantly been provided in-home and usually by one person prior to learning about formal assistance being available. Satisfaction centred on having someone to share caring responsibilities with. There was an acknowledgement that without formal care, relatives would be left to complete all the required care by themselves, and they were therefore grateful for the support they were receiving. Though relatives might be present in the home during care worker visits, this time was viewed by some as an opportunity for respite. Supportive and reliable formal care provision could result in improved wellbeing for informal carers.
‘It would be hard [without formal care services], it would be hard. It’s made it a little bit easier, I mean I can leave [service user] with them and go out shopping or to somebody’s house or go to town. Or they can take her out while I can have a bit of a break. Although I’ve been looking after her, I did courses during the day because if I’d stayed inside then I would have got more depressed.’

(Relative of Female Service user, Pakistani origin, Leeds)

It is possible that some service users and their relatives were comparing the quality of the formal care they received with informal care provided by families, and found it wanting, but they did not say this. The dominant view of the quality of formal home care among Bangladeshi and Pakistani families was positive – they were glad to have the care and, in many cases, their main criticism was that they wanted more of it.

Relatives appreciated it when care workers worked together with, and in support of the family. This mainly centred on good communication between care workers and relatives, but also encompassed trusting staff to be alone with service users, in order to allow some respite for an informal carer.

Furthermore, in cases where service users lived with their relatives, across all ethnic groups, families would oversee and monitor the quality of care provision. One relative explained that she listened to the care worker - service user interaction using a baby monitor.

Care workers of South Asian origin, working for an ethnic specific service highlighted the challenges of working with their Asian clients who live together with extended family. The challenge this presented was having to manage the expectations of the family as well as the client’s, particularly because there was a lack of clarity in some families about the distinction between professional homecare and domestic services.

‘White folks … they used to be very grateful. But once I started for [care provider] and they was all Asians...they want something else.’

(Care worker)

The view was that family members expected care workers to carry out tasks beyond those set out in the care plan, such as cleaning windows or washing clothes for the whole family. This could result in conflict between the family and care worker. Care workers said they felt under pressure to carry out these tasks because families complained if they did not do so. One care worker felt that the problem often lay with service users’ families rather than service users themselves. She said that that one of her clients was an older Pakistani woman living alone, who always thanked her for her work and never put pressure on her to carry out tasks outside the care plan.

Care providers emphasised the importance of ensuring that relevant family members understood the concept of a care plan and the type and frequency of care that would be
available and the role of the care worker. Care workers believed that managing expectations at the start of the process of providing care was the key to a good relationship with other family members.

5.2 Quality within homecare services

5.2.1 Punctuality and time use

Care workers experienced time pressures in completing their tasks within the allotted timeframe and fitting in travel between clients’ homes. These pressures were felt by service users and care workers alike, regardless of ethnic background or care need. Though service users and relatives appreciated that care workers had demanding workloads they reported dissatisfaction when care workers were late. Dissatisfaction was exacerbated when care workers did not notify them of their late running. Unexpected lateness caused anxiety for service users and was frustrating for relatives who relied on staff for assistance and respite.

“You’re looking at your watch and one o’clock comes and they’re not here and two o’clock comes and they’re not here and you start then to get anxious. Are they gonna come, aren’t they gonna come?’

(Service user, male, white British, Leeds)

Service users felt uncomfortable when care workers rushed their work; it gave the impression that they were not taking the task seriously. Furthermore, completing the required tasks and leaving the service user’s home before the allocated (and entitled to) time was up provided a cause of dissatisfaction, for example, leaving after 20 minutes when a 30 minute slot was allocated.

Being allocated tight or insufficient timeslots leading to care workers being unable to complete tasks fully, was a widespread issue. One service user explained that once the allocated 30 minutes were up, her care worker would leave, even if the task had not been completed. Though this is not directly related to care workers themselves but rather an issue of budget allocated by social services, it did affect satisfaction with care workers. Homecare workers echoed these frustrations, and felt that even if they were dedicated, it was hard to carry out the work to a high standard because often they were not given enough time to carry out the tasks set out in their clients’ care plans. Half-hour slots in particular were criticised:

“I don’t think you can wash and dress somebody and breakfast somebody in half an hour.’

(Care worker)
Homecare workers pointed out that they were not paid for staying beyond their allocated time and that often they were forced to leave immediately to visit another service user. This meant they had to rush, which could upset service users:

‘They think you are rushing through, but what they don’t understand is that you are paid for only 45 minutes.’

(Care worker)

There were reports of care workers making informal changes to the agreed timings within a care plan, in order to manage the time pressures they experienced. For example, one service user reported care workers arrived two hours earlier than formally agreed each morning to fit better with the care worker’s working day. Service users had not complained to the care provider company, despite the change not being convenient. Reasons for not challenging such issues were: fear of losing a known care worker, understanding of the wider time pressures on care workers, awareness that the care provider company was understaffed and a general distrust of the care provider company. Though there were no differences on this issue across ethnic groups, this was only reported amongst service users aged 60 years and over and living on their own. This may highlight the importance for care provider companies to maintain regular communication with service users and seek feedback on care workers. It also highlights the role that family members play in supporting and advocating for service users, and the potential vulnerability of service users who lack relatives to perform that role.

5.2.2 Poor professional conduct

There were reports of poor professional conduct by care workers, for example, carrying out care work whilst on a mobile phone, seeking extra paid work outside of the care plan; falsifying timesheets; stealing or borrowing household items, food or money and breaking or damaging household items. These behaviours were barriers to building relationships. There was a discomfort amongst service users and relatives in the feeling that a care worker did not want to be there, or provide care. The service user – care worker relationship required trust, and experiences such as these were damaging to confidence in individual care workers and provider organisations, but also in formal social care more generally. However, this type of conduct was not widespread and most dissatisfaction with services was not related to this type of behaviour.

5.2.3 Care worker training

Provider managers and care workers stressed that care work was challenging and low paid. It offered a degree of flexibility but little security, as care workers tended to be on zero-hours contracts. Homecare workers in particular were said to work long hours, due to travel between clients and this time was unpaid. The main appeal of care work to job-seekers was that it required no qualifications. According to one care worker, the result was that people with no interest in care were entering the field, because it was the only job they could get:
‘They’re being forced to come off the dole … they know that maybe care work is probably one of the last professions that you can get into without that many qualifications, because you can be trained up while you’re in the job. And they use it as an alternative to McDonalds or a factory. And sadly, obviously we’re dealing with people not boxes,…some of them [care workers] are simply just not carers.’
(Care worker)

Local authority and provider staff at all levels agreed on the importance of high-quality training for care workers. Many felt that the mandatory training which providers were required to give new care workers was too basic. A senior manager at a home care provider believed that incidents reported in the media were often due to providers failing to train their workforce beyond the minimum standard:

‘We invest an awful lot of our money back in to training, skills and developing our workforce….Look at the care industry in the media and what you read in the papers, there’s a lot of incidents. And when you look into those incidents you will find that the care workers who were delivering that care are through companies who haven’t invested, who have cut corners.’
(Senior manager, home care provider organisation)

Representatives of local authorities and social care providers linked poor-quality care to the poor conditions and inadequate training experienced by many care workers, and the low prices expected by local authorities. Providers believed that better conditions (including higher pay) and better training led to lower turnover among staff and a higher standard of care. A manager at a homecare provider said that the organisation paid its staff well above the minimum wage (‘we think you get what you pay for’) but believed that many of their competitors did not do so because social care contracts were awarded on the basis of price rather than quality:

‘Although the local authority and government give all this spiel about quality, the driver for this industry is price.’
(Senior manager, home care provider)

A local authority manager echoed this view, suggesting that providers and their staff needed to be paid more:

‘It’s about … recruiting the right people, providing the right contract price. … I still don’t think always that private providers – I don’t know how they deliver quality care sometimes on the rates that are provided. So I think there’s some financial improvement that has to take place.’
(Senior manager, local authority)
5.3 Appropriate care provision

5.3.1 Agreeing a care plan

Homecare providers carried out their own assessments and reviews for individuals. Assessments provided an opportunity for care providers to identify the specific needs of service users (and their relatives), manage expectations and discuss care worker matching. One homecare provider welcomed as many people as possible to be present at assessment and reviews as this facilitated information gathering about the service user.

Assessments were translated into a care plan. One homecare provider asked service users to review and approve the care plan before it was finalised. They wrote care plans in the first person, in order to personalise them. Service users were provided with a copy of their care plan along with advice and an information pack on issues such as safeguarding, how to request a review or make a complaint. The company, however, was only able to provide this information in English.

Local authority and provider staff talked about the importance of listening to service users and involving them in decisions about their care. One local authority had a co-production programme which included gathering feedback from service users. It was widely felt that care should be ‘personalised’ by treating service users as individuals and talking to them about what they wanted, instead of making assumptions based on their background, including their ethnicity:

“Work with the service user and listen to their needs. A particular service user will say, “I want someone from my community because she speaks my language. I like it – somebody comes in, in the day and I can speak my language.” Or, “I confide in her.” Or, “It’s like a daughter coming to the door.” Whereas another service user will turn round and say, “It’s my private life. I don’t want somebody to come in and intrude and ask me all questions about – where’s your daughter? I don’t want any of that so send me a care worker that’s not from the community.” So … you’re listening to the service user and what they need, on an individual basis, and not generalising.’

(Senior manager, homecare provider)

Service users and relatives appreciated having regular contact with managers within care provider organisations, as this provided them with the opportunity to be involved in decision making about their care. There were cases in which care provider organisations were not proactively in contact with their clients, and as a result care services were not reviewed.
5.3.2 Providing culturally sensitive homecare

User and family preferences for ethnic or religious matching

Homecare provider managers and care workers believed that the best way to meet the needs of service users from different ethnic groups was to match care workers to service users on ethnicity, gender and, if possible, language.

‘The only solution is if carers are from the same background when possible, especially with the older generation, as the cared for.’

(Care worker)

A group of care workers thought that matching care workers (and ideally social workers) to service users could also help to break down the suspicion and mistrust which they believed some members of black and minority ethnic groups felt towards people in authority.

Homecare provider managers and care workers said that it was standard practice to match on ethnicity, gender (one manager said that they always refused requests for opposite-sex care workers) and language, although this could cause delays. One local authority manager believed that matching on language was not essential for homecare, but this view was not widely shared.

Interestingly, no providers were said to offer training on culturally-sensitive care (apart from generic equality and diversity training). It was generally felt that such training was unnecessary as long as the workforce was diverse enough for care workers to be matched to service users on ethnicity, gender and, if possible, language.

For many Bangladeshi and Pakistani families it was important for home care to be provided by people who shared the language, gender and, in some cases, ethnicity and religion, of the service user. In some cases this was for practical reasons – so that the family could communicate with the care worker, for instance:

‘I want a Bengali. If a new person comes I have to repeat everything. If he is Bengali, I can at least talk to him and give the necessary instructions. If he is English I cannot talk to him.’

(Relative of male service user, Bangladeshi origin, Birmingham)

There were practical benefits from having a care worker from the same background, for example they knew how to prepare culturally appropriate foods. For some service users, the provision of Halal food (food permissible under Islamic Law) was of paramount importance. The relative of a young service user felt that a care worker with a similar cultural/faith background could be trusted with the task of ensuring that only Halal food was provided to her daughter:
‘I think it’s very important to understand, to have the same background. I mean as far as their, it’s only because of the food and halal comes into especially if my daughter go out, I need to make sure whoever is supporting my daughter make sure that she eat halal food, and they should know how important it is because culture and religion is very important because these are the recognition for our children and other people should respect that.’

(Relative of a female service user, Pakistani origin, London).

Shared cultural practices were considered useful, even where there were no religious requirements. This included an understanding of spices and the skills to prepare traditional South Asian dishes:

‘They [the previous white care workers] were alright and everything, but because we cook Asian food they couldn’t cook for [the service user]…They were English you see…they couldn’t do anything (laughs) like make our food’

(Relative of a female service user, Pakistani origin, London).

There was a feeling of familiarity from having a care worker from the same background which therefore helped some service users and relatives feel at ease.

‘If a white person came to the door and said ‘I’m a cleaner and I’m here on behalf of the social services to help you’, [my mother] would definitely not open the door.’

(Relative of female service user, Pakistani origin, Leeds)

In some cases religious matching was more important than ethnic or language matching. A typical scenario described by a service manager was an expressed preference by service user of Pakistani origin to have a care worker from a Somali background. The Somali care worker would understand the importance of the Muslim faith and associated rituals and practices but would not understand the language spoken in the home (Urdu). This offered the service user and their family a level of privacy.

Another benefit of a shared religious background (irrespective of ethnicity) cited by service users was the ability to discuss their religion and to share religious rituals with the care worker. Although, shared religious belief was not identified as a factor in effective care provision, it enhanced familiarity and provided opportunities to make the care worker-service user relationship more personable. Increased personalisation of care through shared heritage and experiences contributed to service users’ satisfaction with social care.

Even where religious matching was not possible, a homecare worker believed that accommodating religious practices (such as working around prayer times) was important, even though it could make their job more difficult:

‘You want to get your thing done but you’ve got to respect their wishes, and you’ve got to get out of the way and let them pray and go back in.’

(Care worker)
Religious needs could also be met through appropriate equipment or adaptations, not just through care workers. For example, appreciation was expressed by a service user with mobility issues for whom an accessible adapted bathroom had been installed. This allowed the service user to carry out prescribed cleansing rituals for praying.

The importance of religion in the lives of service users was not restricted to a preference for Muslim care workers. An acknowledgment of faith or religious belief provided a common topic of conversation. This presented an important way to communicate on a more personal level with the care worker than would have been possible if the care worker had only been task oriented:

> ‘I used to have conversations about religion particularly because he [care worker] had been involved, with, [the] Mormons for a while. So he was quite interested to speak to me, as a Christian and a professed Franciscan, to see what sort of things that we, you know, we did. We used to have some quite interesting debates about various things within religion, so it was quite good.’

(Service user, Male, white British, Birmingham)

**Provider approaches to ethnic and religious matching**

Some of these families had had to struggle with the local authority to obtain ethnically-matched home care – and had generally succeeded. Others indicated that the local authority had been sensitive to their needs. Meeting the ‘ethnic matching’ request of services users varied across providers. Specialist services such as those providing targeted provision for specific ethnic groups were more able to accommodate service users' request because they employed more care workers from black and minority ethnic groups than providers offering more generic homecare provision.

There was evidence that homecare providers discussed service user and care worker matching during initial assessments with service users. Most care providers advocated having an open discussion about the characteristics service users and their relative did or did not want in a care worker; including preferred gender, ethnicity and language of a care worker. One home care manager explained how they aimed to offer a service that meets the service user’s needs, and the importance of not passing judgment on their stated preferences.

> ‘We’re not here to educate people, we’re only there to deliver a service. And people in their own homes do have the privilege of discriminating. So they can say who they want or don’t want in their house, that’s their right, and we give them what they want. However, if they do discriminate somebody after we’ve given them what they wanted, then that’s not acceptable and we would deal with that.’

(Senior manager, homecare provider)
This approach also reflects an understanding that individuals may not wish to be exactly matched with their care worker on all characteristics and that matching needs to reflect the wishes of the individual. On the other hand, some providers did not want to discuss ethnicity directly with service users as they were worried about accusations of racism.

Where matching was less of a priority

There were Bangladeshi and Pakistani families who were clear that they did not expect care and support workers to share their background. One compared social care to medical care in this respect:

‘They are here to do a job. When we go to hospitals we can’t expect staff to be Muslims or from the same background as us.’

(Male service user, Pakistani origin, Leeds)

White British families often said that it was important for care and support workers to be able to speak English and, in cases involving personal care, to be of the same the gender as the service user. Some preferred white care workers, but the ethnicity of the care worker tended to be less of an issue for them than it was for Bangladeshi and Pakistani families, and had not led to disputes with their local authorities and did not appear to be a significant cause for dissatisfaction with services.

One care worker felt that it was important to provide English-speaking care workers to English-speaking service users. She said that she had come across a white British service user who had been cared for by two care workers who did not speak English and were under the impression that the service user was blind, which was not the case. Another care worker believed that a white service user might prefer a white care worker but feel uncomfortable requesting one, for fear of appearing racist:

‘A white person wouldn’t feel comfortable to say, “Could I have another white person?” because they’d feel ... like they’re being racist or ... they’d feel uncomfortable to say that ... which is a shame, because ... if that’s what their preference is I don’t see why they shouldn’t get it just because it's the other way.’

(Care worker)

People’s expectations of what they wanted in a care worker could change over time based on experience. For example, service users reported initially wanting a care worker from the same background or being anxious about having someone from the opposite sex providing personal care, however due to the professional conduct of the care worker they found that their expected discomfort was not experienced. It is therefore important to review care worker-service user relationships over time. Ultimately, having options, knowing what they are, and the service user feeling they had a say in key decisions about care workers was important.
5.4 Out of Home Care Services

5.4.1 Day opportunity facilities

Generally, service users across all three ethnic groups were satisfied with day opportunity provision. First and foremost day services provided an opportunity for service users to spend time out of their home, participating in activities and having social contact with peers. Service users discussed the positive impact this had on their mental health. Some service users described day centres as a ‘lifeline’, and the feeling they were a ‘second home’ or a ‘family’.

Consistency of service was important. Service users reported having attended the same day service for a number of years. Staff played a central role in the level of satisfaction experienced by service users. Service users liked engaging staff who spent time with service users (rather than being in an office). They also liked staff who were supportive and encouraging, and responsive to service user requests and feedback. Service users wanted staff at day services to be caring, just as they wanted homecare workers to be caring. There were reports of poor service from day service staff; problems centred on staff not spending sufficient time with service users and being unfriendly or intimidating.

The consequences of budget cuts were a source of dissatisfaction, for example, redundancies of established and well liked staff, fewer and a smaller range of activities on offer and less staff time available for service users. One service user of Pakistani origin, with a visual impairment explained that she felt excluded at her day opportunities service, as she was not able to participate in all activities on offer due to staff shortages. Under resourced day services resulted in understaffing and stretched resources, leading to those with the most challenging needs feeling sidelined.

Service users liked having a range of activities available to them, and the opportunity to request new and different activities. This again highlighted the importance of being involved in decision making processes about social care. Service users described being bored at day services where there were limited activities or no variety in the activities available. One relative of a non-verbal service user of Bangladeshi origin, with complex needs described dissatisfaction with the day service he attended, as staff left him strapped in his wheelchair all day and did little to engage or challenge him. However, his attendance at the day service offered the family respite, and he therefore continued to attend.

Local authority and provider staff agreed that it was essential to be able to offer culturally sensitive social care. They gave examples of the problems which could arise when local authorities or care providers did not take into account the language or cultural background of the service user. For instance, a day centre in one local authority was said to provide no food apart from sandwiches, which the centre’s South Asian service users would not eat. Bangladeshi and Pakistani service users who had experience of attending ethnicity
specific day centre services, liked the opportunity to speak to peers, having staff that could speak the same language, culturally appropriate food, and facilities such as a prayer room. However, ethnic specific services in themselves were not a source of satisfaction, as poorly run services resulted in dissatisfaction. Supportive and engaging staff and having a range of activities available remained important within ethnic specific services.

Despite some of the examples highlighted above where day services were not provided appropriately, among providers we spoke to religion was not seen to be a major issue for day opportunity services as adjustments could readily be made. One day care manager said that their service users had religious differences relating to food but that the centre had found ways of coping with these. For instance, service users who were fasting were not asked to attend cooking lessons – they were offered other activities instead. The centre provided vegetarian food only, as this was suitable for all their Asian clients, and covered all religious dietary requirements.

Day service provider managers said that they tried to match on ethnicity and gender (some centres were entirely female, for instance) but matching on language was more difficult. Day services specialising in care for South Asian populations tended to have staff from a range of South Asian backgrounds. Managers said that it was not always possible to match service users to members of staff who spoke the same language. For instance, one said that they had struggled to recruit Tamil and Malayalam speakers. As a result, staff sometimes had to rely on gestures and broken English:

'We get by with interpersonal skills and broken English and signs'
(Senior manager, day opportunities provider)

‘The staff are very aware of people's cultural needs anyway and, because of that, hopefully we're not making massive mistakes. ... I think if you don't match the right staffing, then presumptions can be made and that's where things just fall flat on their face.’
(Senior manager, day opportunities provider)

Specialist South Asian services provided generic information leaflets in a range of different languages to cater for BME groups. However, there was a reluctance to translate all documents as standard, particularly those that are likely to need updating over time, due to the cost associated with translations. Specialist providers described how their target groups preferred to receive information verbally, rather than written materials. Verbal communication could be personalised and was therefore felt to be more effective.

Day opportunity services and their staff often took on a wider support role for service users and relatives. In some cases they provided support in contacting social services and monitoring the changing needs of service users. Asian specialist day services in particular were a bridge between social services and Bangladeshi and Pakistani service users and relatives; assisting them in understanding and navigating the local authority care system. Where day services provided this type of role, it contributed to satisfaction with the
services received. The only dissatisfaction with this wider role was when day services reported suspected concerns to social services about relatives’ treatment or ability to cope with the service user.

5.4.2 Transport services

Two different types of transport services were discussed: day centre transport services and Local Authority Dial-a-Ride. Service users appreciated having day centre transportation services. Satisfaction was reported when this service was flexible; for example when relatives were running late and asked for a later drop off for the service user. However, dissatisfaction was reported when a service user had to be on the transport service for long time (e.g. always being the first to be picked up and last to be dropped off) as this was felt to be a waste of time. In terms of Dial-a-Ride, dissatisfaction was related to late or early arrival of the service.

5.4.3 Meals on wheels

There was a general dissatisfaction with meal on wheels services. The main issue experienced was poor quality foods being provided at a high cost.

‘They’re charging £4.10 pence for a dinner in which there’s a tiny pudding which you wouldn’t feed to a dog, to be honest, but now, because [the] Council has removed their subsidy, they’re going to go up to £5.71.’

(Service user, male, white British, Birmingham)

Other issues reported were: meals not delivered at the right time of day, for example a hot lunch sent in the morning; meals delivered still frozen or cold rather than warm as expected. Having unsuitable foods delivered was also an issue – for example delivering food that required chopping to someone who was unable chop or delivering meat when non-meat options were requested. Meals on wheels were received by service users from all three ethnic groups and none of the issues we identified were culture or faith related. Issues relating to culture, faith and food were raised by Asian participants in relation to ethnic matching of home care workers.

5.4.4 Respite services

Dissatisfaction with respite services was two-fold: firstly, there was frustration around allocation of funding for respite. Service users and relatives, in some cases, wanted the option to use respite funding to hire a respite care worker to provide care in the service users’ home rather than residential respite care home. Furthermore, there were frustrations when respite had to be self-funded, as it was felt that local authorities should offer this service as standard. Secondly, there was a dislike of local authority respite care homes. They were not felt to be homely; there was a dislike of sharing bedrooms and bathrooms with others, and not being able to take pets. These findings cut across ethnic groups, there were no clear differences between groups.
6 Discussion and recommendations

6.1 What drives satisfaction

This research has shown that service users’ experiences of local authority care and their satisfaction with services are driven by three key elements in the process of obtaining and receiving care. These are first, finding out about social care services and making contact with the local authority; second, relationships and interaction with social workers; and third, the way in which individual care and support workers deliver the care. We found consistency across the three ethnic groups included in this study in terms of what would contribute to satisfaction and dissatisfaction with each of these elements of social care. However, the research also identified some additional cultural, language and religious factors which affect how Bangladeshi and Pakistani service users access and receive local authority social care. Where services were delivered without regard to the additional barriers or cultural needs faced by these groups, this could lead to lower levels of satisfaction than among the white British group.

We first outline the consistent drivers of satisfaction across ethnic groups and then go on to discuss issues faced particularly by the Bangladeshi and Pakistani community. Some of these can be generalised to other minority groups, and others may be specific to these two communities. It is notable that, although we included two different South Asian communities, clear differences were not found between them in terms of experiences of receiving care and levels of satisfaction.

6.2 Common drivers of satisfaction

6.2.1 Satisfaction with access to local authority social care

In order to be satisfied with access to social care potential service users needed to be aware of services, be able to make contact with the local authority and receive an assessment in a timely manner. Budget cuts which reduced people’s care packages or meant they received less care than other people who they believed were in a similar situation were a source of dissatisfaction. There was a consistent finding that service users and their families would like to receive more care than they currently do.

6.2.2 Satisfaction with social workers

Service users of all groups expected consistency in social workers; frequent changes of social workers without adequate handovers were a source of dissatisfaction. Service users also expected to be able to make contact with their social workers and to have regular contact with them in a reliable manner, with visits from them when they had been
arranged. Where service users or their families were unable to make contact (because they did not have a number for the social worker), this was likely to be a cause of dissatisfaction. Service users also expected their social worker to be concerned about them. Service users relied on social workers being knowledgeable about the system and being able to help them access an appropriate care package.

6.2.3 Satisfaction with care received from care and support workers

This element of the care journey was the most important in terms of driving satisfaction. The care and support workers were the people who service users and their families had most contact with and who were responsible for actually delivering the care. Service users and their families were satisfied when care workers were professional but also caring and personable, arrived promptly and completed the tasks they needed to do without giving the impression of rushing. What mattered was not just that the task was done but that it was done in a manner which meant the service user felt ‘cared for’. Service users from all groups were most satisfied when care and support workers went ‘above and beyond’ by completing additional tasks which were not on their care plan or by staying for longer. Care workers were found to be under a great deal of pressure with short time slots, inadequate travel time provided and low pay. This could result in tasks being rushed or workers arriving late. Where the tasks in the care plan could not be completed in the time allocated this resulted in unmet need for care. High turnover of care workers also resulted in a lack of consistency in care and all of these factors contributed to dissatisfaction among all ethnic groups. Nonetheless, there was a recognition among all groups of the financial and time pressures which local authorities and care workers were under.

An unmet need identified across all ethnic groups was companionship to counter loneliness and isolation. Where care workers were able to provide social contact and had a friendly relationship with the service user while completing their tasks, levels of satisfaction appeared to be higher.

6.3 Drivers of satisfaction which varied by ethnic group

In this section we discuss a number of issues which contributed to differing satisfaction among Bangladeshi and Pakistani service users compared to that expressed by white British service users.

6.3.1 The role of culture and religion in satisfaction with social care

There is substantial published evidence on culturally determined help seeking behaviours and debates on what might constitute an appropriate intervention or response (Astin et al, 2008; Gask et al, 2011; Parveen et al, 2011). Service users taking part in this study clearly suggested that the interplay of culture and religion influenced their level of satisfaction with social care. This was mainly expressed with reference to the attitudes and beliefs of older service users.
The view that South Asian families ‘take care of their own’ can reduce access to services so that individuals may have been cared for in the family for many years before social services become involved. There is evidence in the literature that this view is often expressed by professionals and by family members not directly involved in care (Mir and Tovey, 2001; Atkin, 1995). Often help with social care was sought when families reached a crisis point. This may mean that families are grateful for an intervention (any intervention) from social services or they may feel little satisfaction as the process of receiving care may take time. Where care is only sought at a crisis point, any delay in obtaining help can be problematic.

The ‘we take care of our own’ attitude expressed by some services users was sometimes matched on the part of social services by the response that ‘they take care of their own’. This can create a gap in communication and in the provision of adequate services. Some concern was expressed by service users that Asian families may receive lower levels of care and could be discriminated against by social services. The traditional view that South Asian family support was available resulted in a perceived inadequate response from social services. In this study there was no evidence of social services mistakenly assuming people lived with relatives when they did not, however it is clear that local authorities considered help given by family members when deciding on care packages.

This view of social service attitudes to providing care for these groups may mean that individuals in need and their families may be more reluctant to approach social services. The combination of this perception with poor understanding of the system, little knowledge of individual rights and communication difficulties can result in a wide ‘cultural gulf’ characterised by entrenched stereotypical views, concern about ‘outsiders’ entering the home, and concerns about the stigma associated with needing care which can delay access to care (see also Mackenzie, 2006). Concern about the stigma of receiving care from outside, even when it is needed may also affect how users and their families express satisfaction. There was evidence of concern about what others would think of them being seen to receive visits from care workers.

Bangladeshi and Pakistani service users were more likely than white British service users to be living with family. This had several impacts on satisfaction with social care. It was common for family members to provide most of the care needed by service users, with only limited care being provided by the local authority. There was also evidence of some misunderstanding of the care worker’s role and the fact that they were only there to perform specific tasks for the service users. Care workers had to interact with family members and carers as well as the service user and rapport had to be developed with the whole family. Where service users and family members had differing views, particularly in relation to cultural or religious needs, this complicated the delivery of care that was on offer and affected satisfaction with the services. Dissatisfaction was experienced when local authorities and care workers did not consider the needs and contribution of other family members when providing care.
Personal budgets received through direct payments, which allow service users to choose services which best meet their needs, or to pay family members to provide care were a potential source of satisfaction for Bangladeshi and Pakistani service users and their families since they allowed care to stay within the family or the community. However, on occasion they could be a source of dissatisfaction because of the difficulties of managing them.

The complex interplay of assumptions and expectation of care, expressed in cultural and religious terms by service users and corresponding responses from social services may result in some service users expressing satisfaction with a lower level of care than is actually needed. For other service users with higher expectations of care, dissatisfaction with inadequate (or inappropriate) care responses can result from, sometimes misplaced, cultural assumptions of services providers. There are also situations where cultural differences result in a misunderstanding of the scope of what social care services can provide and unrealistic expectations among care users.

6.3.2 Language and communication barriers in accessing and using social care services

At all stages of accessing and using care, we found evidence of barriers to communication which were a particular problem for Bangladeshi and Pakistani service users and their families. This started with difficulty in contacting the local authority by phone where phone systems are often automated and contact centre staff did not speak languages used by service users. Communication with social workers was hampered by the lack of a shared language and inappropriate or non-existent translation services.

Service users from all ethnic groups described the need to fight to get the services they believed they needed. Going through the processes needed to successfully challenge local authority decisions required good English and an understanding of how the system worked, which Bangladeshi and Pakistani service users were less likely than white British service users to have. Where service users faced these types of barriers they could be overcome by the intervention of family members, community organisations and day services. This also meant that, it was not just language skills which mattered but education and familiarity with how things work in Britain.

While lack of a common language was not an insurmountable obstacle to good quality care and good relations with individual care and support workers, it did make the relationship more difficult. For example, the service user relied on family members to explain things and when the care worker changed it was difficult to explain the routine or where things were to new care workers. However use of song or appropriate greetings such as ‘auntie’ combined with a friendly approach did enable care workers to develop good relationships with non-verbal service users or those who did not share a common language.
This research also found an issue of ‘hidden’ female carers, who take much of the responsibility for caring for parents, parents-in-law and children but who have limited contact with social services because of language barriers and the pressure of other responsibilities. Members of this group felt the need for support but did not know how or where to access it.

6.4 Ethnic matching as a response to cultural and religious difference

Ethnic matching – that is the allocation of a social worker or care provider who matches as closely as possible the ethnic, faith, dietary, and national and/or linguistic characteristics of a service user (along with gender matching) is a standard social care response.

Service user views on the value of ethnic matching between service users and care workers were mixed. In some instances, family members expressed more concern about ethnic matching than service users. The division of opinion meant that for some service users, ethnic matching was a significant driver of satisfaction, but for others it had little effect.

Service users and their relatives held a range of views on the type of ethnic matching they preferred. The issue of privacy and confidentiality played a role in service users’ request for a care worker from a different ethnic or community group from their own. In such instances service users still wanted care workers to have an understanding of faith and cultural issues. Providers believed this preference was at times driven by family members who were worried about how members of their community would react to their reliance on professional homecare or because the service user lived in an extended family unit and was worried about care workers overhearing private family discussions.

Even when taken separately from the importance of a common language for effective communication, ethnic matching remained an important factor in some Pakistani and Bangladeshi service users’ satisfaction with their care and support workers. Two key themes were evident as an explanation for desiring ethnic matching – firstly, an increased level of familiarity because of shared cultural factors, and secondly the expectation of a more tailored level of care with potential practical and social benefits. The ability of service users to communicate and interact with their care workers in culturally meaningful ways adds an aspect of ‘caring’ into care. Developing rapport is directly related to service users’ desire for social contact and meeting this need can increase satisfaction with social care.

Ethnic matching appeared to counter to some extent the concern about ‘outsiders’ in the home and seemed to increase levels of trust in services. Service users’ spoke of feeling safer with someone from the same ethnic background, even highlighting an unwillingness to allow a care worker from a different background through their front door. Service users felt more comfortable allowing someone with a shared heritage to enter their home, and
provide what could be very intimate services that could put the service user in a vulnerable position.

The ability of local authorities and provider organisations to offer ethnically matched care depended on the availability of suitable workers. The local workforces did not always reflect the ethnic mix of the service user population meaning compromises had to be made about what was matched (e.g. language, culture or religion). Provider organisations also varied in the extent to which they discussed preferences for matching of different types with service users. Organisations which did not discuss ethnic preferences with service users were sometimes concerned about issues of racism.

As well as expressing positive preferences for care workers of the same ethnicity or background, some service users or their relatives taking part in this study also held negative views about the ethnicity of care workers which was different from their own. Among the white British group, these views could be long-held stereotypical beliefs based on care workers racial characteristics which in some instances resulted in service users referring to care workers in racially derogatory terms. There was evidence of instances where dissatisfaction with care was attributed to care workers ethnicity or racial characteristics and then extended to all care workers with similar characteristics. Difficulties in communicating with care workers with a poor grasp of English were also identified as an issue that led to the stereotyping of care workers.

The types of prejudices expressed by service users of Bangladeshi and Pakistani origin focused more on care workers’ national origin and their ability to carry out tasks effectively. This could work in several ways which could lead to a preference for ethnic matching or against matching. In some instances, service users were of the opinion that white British care workers, perhaps because they were more task-oriented, were better at handling practical personal hygiene tasks such cleaning or changing clothes. Another interpretation could be cultural notions of body modesty affect how personal hygiene tasks are carried out care workers of South Asian origin. This shows that although a common cultural framework was valued by some service users, ethnic matching has its limitations and can result in increasing dissatisfaction with social care.

Across all service user groups, irrespective of ethnicity, national origin or age, there were service users and relatives who expressed the alternative view that ethnic matching was unnecessary and the race or ethnicity of care workers was not the most important factor in the provision of quality care. Services users underlined the importance of care workers’ professionalism and ability to do the job well. What is evident from service users’ perspectives is that an overly task-oriented care worker who is not able or willing to establish rapport or a good working relationship with service users could lead to dissatisfaction with care. In the case of service users of Bangladeshi and Pakistani origin, the establishment of a “good working relationship” may require care workers to have an understanding of cultural norms and practices to deliver care that is personalised enough to signify rapport (Gask et al, 2011). While ethnic matching is useful in bridging the cultural gap, the social norms and personal approach suggested by service users can
potentially be understood and adopted by care workers of any ethnicity or faith background. It is also clear, given the widely differing views of ethnic and religious matching, that a person centred approach which considers the specific needs and preferences of the individual, rather than an assumption that ethnic matching is best, is most likely to lead to satisfaction with the resulting care.

6.5 Meeting service user needs

Care worker behaviour, attitudes as well as their individual approach to addressing cultural differences appears to define the parameters of care worker-service user interactions. Service users clearly understood that care workers are paid to carry out specific tasks that do not include the role of social companion. However, the ability of care workers to adapt their task-oriented role to personalise care by interacting socially with service users influenced how service users felt about receiving care. This was the case for all ethnic groups, but for Bangladeshi and Pakistani service users there was an additional cultural dimension to this which affected satisfaction. This included culturally appropriate forms of address being used, prayer times being accommodated and appropriate food being prepared.

Culturally appropriate care was also particularly relevant for those participating in activities outside the home, for example at day services. Gender segregated activities, such as separate exercise classes for men and women, increased satisfaction with available services. Similarly, the provision of culturally appropriate enabling equipment or modifications in the home was considered important for overall satisfaction with social care.

6.6 Why is satisfaction with social care lower among Bangladeshi and Pakistani service users?

This research asked whether differences in satisfaction with social care in survey data reflect inconsistencies in the measurement of satisfaction and what lies behind any genuine ethnic differences in satisfaction. The cognitive testing survey of questions as part of this project demonstrated that although the survey questions have some limitations, they collect consistent and comparable data across ethnic groups. The qualitative element of the research has shown that while there are common drivers for satisfaction with social care across groups; there are language, religious and cultural differences between ethnic groups which can lead to lower satisfaction with social care where care is delivered in a way which is not sensitive to these differences and the preferences and needs of individual service users.
6.7 Recommendations

The recommendations outlined below resulted from three deliberative workshops held at the end of this project in Leeds, London and Birmingham in October and November 2013. Participants heard the key findings of this research project and then discussed these in groups. It should be noticed that some of these recommendations are not ‘new’ – they reflect good practice which is already happening in some areas, or what would happen if existing guidelines were followed. This report brings these together in the context of a detailed understanding of the experience of accessing and receiving social care for three specific ethnic groups. The aim is to share this good practice and highlight where our findings suggest that relatively small changes could make a difference to satisfaction with social care.

6.7.1 Local authorities’ understanding and engagement with minority groups

- Local authorities need to profile their local populations and have a workforce that reflects this profile, or at least represents the main groups within the local population.

- Having frontline local authority staff with relevant language skills was also recommended, as a way to improve the process of seeking information about social care services for people with limited English. Translated written materials are no substitute for this, since people may not be sufficiently literate and the translations can be inappropriately formal in style.

- Local authority outreach work was thought to be beneficial to raise awareness of support available. The following targeted approaches were suggested:
  - Awareness raising through community media (such as community radio).
  - Staff at GP surgeries with large populations of BME patients could be briefed to prompt patients to take leaflets; or outreach work could be carried out in GP surgeries.
  - Local authorities could engage with community and religious organisations to spread information and carry out outreach work. Staff at outreach events should be able to speak relevant languages.
  - Local authorities should in particular, consider how to reach out to South Asian women who may well be ‘hidden carers’ and may not speak fluent English. One suggested approach was to carry out outreach work in locations such as Asian specialist supermarkets and nurseries and primary schools.
  - Promoting direct payments and personal budgets, in particular, was suggested as a way to engage BME groups with social support services.
  - Local authorities should be mindful of translated information; engaging with community organisations may help sense-check materials and ensure they are meaningful to communities.
  - Such campaigns and awareness raising activities need to be carried out periodically to ensure coverage amongst existing and potential future users of social care.
- Local authorities may also want to carry out reviews to assess how well their services and known about and used, especially by minority groups within the population.

- Local authorities should have a clear and accessible website providing information about their adult social care services. The Birmingham website ‘My care’ was cited as an example of good practice.

- Navigating the social care system could be made easier for people by having a policy of user friendly language across all areas of the system - from websites to assessments.

- Local authorities (and the NHS) should ensure their re-ablement services staff, in particular, have cultural awareness training and are able to engage with BME clients; as this may be the first point of contact with social care services for many people.

- Local authorities should embed ethnicity at the beginning of the service commissioning process for all services and diversify the provider market to reflect the needs of the local population.

- Local authorities should share good practice with one another on methods for engaging with and improving access for BME groups.

6.7.2 Reducing Stigma

- Media support from within minority ethnic communities was suggested as a way to reach and influence service users and families as well as the wider community. Discussion pieces on local community radio could help break down stereotypes about needing care and the stigma of using social care services.

- Local authorities could appoint champions who could work to promote positive views about services and increase trust within communities. Existing service users from BME communities could talk about their experience to reduce stigma.

- Local councillors could be instrumental in bringing different community groups together around particular campaigns, for example awareness raising about care services, local authority support and perhaps even issues about hidden female carers.

- If care and support workers did not wear a uniform when going to homes of service users it would be less obvious that social care was being received. This many help reduce possible fears of community gossip and stigma.

6.7.3 Social workers

- Social workers should be supported in working with minority clients. The following suggestions were put forward as possible ways to achieve this:
- Cultural awareness training: training needs to be ongoing and go beyond basic information; training should challenge common assumptions made about BME groups; be focused on equipping social workers to work with BME clients; include learning basic words of (locally relevant) languages as a way to help establish relationships; training should also include information about religious needs and values.
- Training should also encourage social workers to move away from assumed knowledge about BME groups to a policy of asking service users about what kind of support would be appropriate.
- There is a need to increase social workers’ experience and involvement in working with people from minority backgrounds.
- Social workers could benefit from connecting with specialist minority carers’ forums.
- Training and mentoring could be provided through community groups.
- Social workers should also receive training on how to use interpreters effectively.
- Social workers should be alerted to significant cultural dates and events. One way to achieve this could be through computer screensavers about upcoming religious festivals and their importance to different populations. Local community groups could be brought in to speak about religious festivals and share culturally appropriate foods.

- The same social worker should be present throughout a service user’s care journey to build trust with individuals and in communities. If this is not possible, social workers should give and be given thorough handovers. This would apply to all groups, including white British. In the case of BME service users, the handover should involve relevant information about culture, religion and language specific to that person.

- A pre-meeting ahead of formal assessments may help to empower service users and give them more control over the process. Meetings could be used to give service users and their families information about what they should expect from social workers and the aims of further meetings.

6.7.4 Interpreters

- Local authorities should have a policy of not using family members as interpreters within assessments and meetings with social workers; to avoid misinformation, and breaching confidentiality of service users.

- Trained and accredited interpreters should always be present for meetings with social workers and assessments where the service user or family member speaks limited English.

- Interpreters should have experience of interpreting within social care and health settings, and have an understanding of key terminology (or training should be offered).
6.7.5 Communication between local authorities and provider organisations:

- Providers and local authorities may not share information for data protection reasons, however this needs to be overcome so that service users’ basic needs can be addressed. Implementing SCIE’s guide on coproduction of social care services would help overcome many of these issues.

- Key information about the service user which would affect how the provider should contact the service user, how the service would be provided and choice of care workers should be provided by the local authority. This would include information on language, religion, ethnicity and preferences of the service user.

- Once a provider agency has been identified, a joint visit with both provider and social worker could help ensure that service users understand what is included in their care package.

6.7.6 Care and support workers

- Care and support workers working with people from different communities from themselves should be:
  - supported to develop good interpersonal skills with sensitivity to cultural influences;
  - encouraged to develop their own knowledge and interest in finding out more about BME populations;
  - given opportunities to interact with clients from BME communities, as this is an important way of developing knowledge;
  - given training which includes a service user led element which is likely to be helpful in avoiding stereotypical generalisations about particular groups. This would be relevant not only to BME groups but also other minority groups in the population;
  - given training on basic skills in how to introduce themselves and develop relationships with service users from minority ethnic groups and they should be encouraged to demonstrate these from the first meeting;
  - given local authority provided training.

- Local authorities and provider organisations should seek to recruit, train and retain a workforce which reflects the profile of the local population. This could involve:
  - Gaining further understanding about why people from certain communities might not want to work in the care sector and not apply for jobs in social care.
  - Carrying out positive recruitment drives to recruit people from BME communities.
  - Renaming the role ‘care practitioner’ or another term which sounds professional to enhance the status of the profession and attract more BME applicants.

- The quality of recruited care and support workers could be enhanced by:
  - paying travel time and a living wage,
  - improved training and development opportunities.
providers obtaining regular feedback from service users on care being received, either over the telephone, by email or online, and sharing and reviewing this feedback with staff in a confidential and sensitive way.

6.7.7 Service users

- Service users should be empowered to write a case file about their needs, giving some background about themselves, for example, a ‘10 things you need to know about me’; a guide that would be kept at the service user’s home and shown to social workers and care and support staff. This guide could use text, pictures or drawings to illustrate the individual’s needs. The content and style should be guided by the service user.

- Local authorities and care provider companies could develop service user reference groups through which feedback could be given in a confidential way, on services received.

- Service users and families may benefit from training (provided by local authorities) to provide information on the role of care and support worker and care plans, and information on issues such as how to make a compliant. Such training could happen before service users’ first meeting with care and support workers to ensure that service users knew what to expect and when standards were not being upheld.

6.7.8 Gender

- In addition, overlying all these recommendations there needs to be an understanding of the gender dimension to care and how this interacts with cultural, religious and ethnic differences. Carer and care and support worker populations are predominantly women, and cultures and religions vary in terms of expected and appropriate roles for women. This means that in engaging with minority communities, expanding the workforce and meeting the needs of individual service users, the impact on and role of women needs to be actively considered.
7 References


Manthorpe, J., Iliffe, S., Moriarty, J., Cornes, M., Clough, R., Bright, L. & Rapaport, J. (2009) ‘We are not blaming anyone, but if we don’t know about amenities, we cannot seek them out’: black and minority older people’s views on the quality of local health and personal social services in England. *Ageing & society*, 29(1), 93-113.

Mir, G., & Sheikh, A. (2010) ‘Fasting and prayer don’t concern the doctors ... they don’t even know what it is’: Communication, decision-making and perceived social relations of Pakistani Muslim patients with long-term illnesses. *Ethnicity & Health*, 15(4), 327-342.


Yeowell, G. (2010) What are the perceived needs of Pakistani women in the north west of England in relation to physiotherapy, and to what extent do they feel their needs are being met? *Physiotherapy*, 96(3), 257-263.
Appendix A
Service user topic guide used within the qualitative interviews with service users.

P3143 Exploring experiences of social care amongst Pakistani, Bangladeshi and White British populations

SERVICE USER TOPIC GUIDE September 2012

Research aims
- To explore why lower levels of satisfaction with social care are consistently reported by black and minority ethnic groups by carrying out in-depth research with three populations: Pakistani, Bangladeshi and white British social care users, their relatives and care providers

Interview objectives
- To find out about participants’ experiences and views of social care, in particular exploring:
  - Expectations of social care
  - Access and actual experiences
  - Views of social care
  - Suggestions for improvement

As this is an exploratory study, we will encourage participants to discuss their views and experiences in an open way without excluding issues which may be of importance to individual participants and the study as a whole.

The following guide does not contain pre-set questions but rather lists the key themes and sub-themes to be explored with each group of participants. It does not include follow-up questions like 'why', 'when', 'how', etc. as it is assumed that participants’ contributions will be fully explored throughout in order to understand how and why views, behaviours and experiences have arisen. The order in which issues are addressed and the amount of time spent on different themes will vary between interviews and according to individual experiences.
1. Introduction
Aim: to introduce the study, the research team and explain the interview process

- Confirm the name / personal details of the participant
- If recruited by recruitment agency – ask about how they were approached and what they were told about the study/interview. This is to check that recruitment was appropriate.
- Introduction to researcher(s) and research team
- Explanation of study
  - Aims and objectives
  - Timetable, outputs
- Explain details about participation
  - Voluntary nature of participation
  - Confidentiality and anonymity between interviews and in outputs/ reporting
  - Only exception is if interviewer hears about a situation where someone could be at risk of extreme harm or danger might need to include examples
- Recording and secure storage of data
- Informal nature of discussion, coverage of key topics: some personal
  - Interviewee does not have to talk about subjects that they do not want to, if subject is upsetting or difficult they can ask researcher to move on or take a break
  - Discuss where the interview is to be held, whether the participant would like somebody with them or nearby for support during the interview and any concerns participants may have about being overheard
- Provide leaflet with sources of information and support at end of the interview, along with £20 thank you
- Length of interview (up to 1 hour)
- Check whether they have any questions
- Check whether still happy to go ahead
- START RECORDING
- Record on tape that the research has been explained to the participant, in particular the voluntary and confidential nature of the interview (unless someone is at risk of extreme harm or danger), who is present at the interview and that they are happy to take part in the research.
2. Background

- Living arrangements; length of time in current circumstances
- Family and social networks
- Day to day activities
- Overview of health (current as well as in the past, where relevant)
- What social care is being received:
  - Could be for personal care; help with cooking/cleaning/shopping; attending a day centre; receiving money (direct payment) to pay for help of some kind (could be from someone they know); equipment; adaptations; safety buttons; meals on wheels

3. Accessing social care

   **Aim:** to get an overview of participants’ expectations and understanding of social care; how social care was accessed and by whom, what the process was like and whether there were any issues/problems encountered

- What does recipient understand by the term social care
- How was the need for social care identified and by whom
  - What were the needs identified
- Expectations of social care provided by the Local Authority
- Did the social care recipient/family agree/disagree that it was needed
  - If there were any differences how were these resolved
- Find out how social care was accessed:
  - Who instigated and carried out the process and what was involved
  - How long did it take
  - Any problems encountered (details)
  - What worked well/less well
  - Outcome
- If care has still not been provided – explore fully the impacts of this on participant & their family/friends

4. Overview of social care being received

   **Aim:** get overview of participant’s routines and activities; what help they require; what help they receive and from whom

- **Ask participant to describe a typical week**
- Daily routines: getting up; washed; toileted; dressed; managing stairs; cooking; shopping; housework;
  - explore whether participant needs any assistance with these daily activities
  - if so, find out what assistance is received and from whom
  - if help is not being received, what is the impact on participant and their families & reasons why
- Other activities: socialising; working; hobbies and interests
  - Explore whether participants are involved in any other activities and if so,
    - whether they require any assistance,
    - whether they receive any assistance
5. Views on experiences of social care

Aim: understand participant’s views of receiving social care and the impact on them and their family

- NB: this section will need to be tailored depending on the type and nature of social care being received
- Going back to key activities participant receives help with, explore how they feel about receiving assistance with social care activities (start openly)
- Key features that affect the experience and why (general section):
  - Communication with the care provider: clarity/speed/nature of communication/ language issues
  - Timeliness of service provision
- Social care where there is some kind of personal interaction
  - Whether the care giver is known to the participant or not
  - Consistency of provider: whether same person or constantly changing (differences between carers)
  - How the care is organised (whether someone is sent, or whether care receiver organised the care themselves)
  - Attitude of the care giver (positive, negative demeanour)
  - How the care is provided (quickly or slowly; confidently, competently, whether care provider checks with participant about how it is being done)
  - Whether care is provided at the right time (e.g. for getting up in the morning)
  - Communication (language barriers; what kind of communication there is during the care encounter; is communication at the level the participant wants or not)
  - Whether the care giver is of the same or a different ethnicity/ religion / social background/ age group
  - Gender of the care giver

- Impact of service being provided on participant & their family: explore fully i.e. what would happen without it

6. Gaps and suggestions

Aim: to establish what would enhance the experience of care provision

- Participants reflections: what for them are the most important features of receiving care and why
- Any gaps in current provision
Suggestions for improvements
- Overall evaluation of the care received (thinking about formal and informal separately)

**Next steps**
- Thank the participant. Check whether they have any remaining questions about the research.
- Reassure them about confidentiality and anonymity.
- Give them a copy of the information leaflet containing contact details about help and support.
- Give the £20 thank you for taking part
- Ask if they would like to be informed of the outcomes of the research (take e-mail address if that is their preferred way of being informed)
- If participant has time/is not too tired, discuss the next stages of the research:
  - A) Snowballing: do they know anyone else that might want to part in a service user interview
  - B) Relative interviews: emphasising voluntary nature of doing these interviews both for them and the relative, each interview would be confidential (no information shared between one interview and another) and permission from both people separately is needed
  - B) Cognitive interviews: not until at least October 2012
- Otherwise, check if possible to discuss at a later date