

# Ethnic minority customers of the Pension, Disability and Carers Service: An evidence synthesis

by Peter Allmark, Sarah Salway, Richard Crisp  
and Ruth Barley

**Department for Work and Pensions**

**Research Report No 684**

# **Ethnic minority customers of the Pension, Disability and Carers Service: An evidence synthesis**

**Peter Allmark, Sarah Salway, Richard Crisp and Ruth Barley**

A report of research carried out by Centre for Health and Social Care Research,  
Sheffield Hallam University on behalf of the Department for Work and Pensions

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# Abbreviations

|      |   |
|------|---|
| AA   | Attendance Allowance                    |
| BME  | Black and Minority Ethnic               |
| CA   | Carer's Allowance                       |
| CLG  | Communities and Local Government        |
| DCS  | Disability and Carers Service           |
| DLA  | Disability Living Allowance             |
| DWP  | Department for Work and Pensions        |
| ESOL | English for Speakers of Other Languages |
| IS   | Income support                          |
| LFS  | Labour Force Survey                     |
| ONS  | Office for National Statistics          |
| PCT  | Primary Care Trust                      |
| QSM  | Quarterly Satisfaction Monitor          |
| PDCS | Pension, Disability and Carers Service  |
| SHU  | Sheffield Hallam University             |
| TPS  | The Pension Service                     |



# Glossary

|   |  |
|---|--|
| <b>Attendance Allowance</b>                   | Paid to customers aged 65 and over who need help with their personal care due to illness or disability.  |
| <b>Black and Minority Ethnic</b>              | The term 'Black and Minority Ethnic' (BME), and the acronym BME, are used throughout this report as a short-hand way of referring to all customers who are of an ethnic background other than the majority white British. It is recognised that this broad category has limited analytical value and its use is not intended to downplay the significant heterogeneity that exists among and between the diverse ethnic populations of the UK. Wherever possible and appropriate, more refined categories are employed and differential experiences highlighted. |
| <b>Carer's Allowance</b>                      | Paid to customers who care for severely disabled people in receipt of Disability Living Allowance (DLA) or Attendance Allowance (AA).  |
| <b>Disability Living Allowance</b>            | Paid to customers aged below 65 who need help with their personal care because of illness or disability or help with mobility.   |
| <b>Disaggregation</b>                         | Breaking a whole into parts; in this report it usually refers to breaking down figures by ethnic group and other sub-groups.   |
| <b>Pension, Disability and Carers Service</b> | Executive arm of the Department of Work and Pensions (DWP).  |
| <b>Pension Credit</b>                         | Provides a guaranteed income for pensioners through topping up to a minimum level.   |
| <b>State Pension</b>                          | Paid to customers who have reached pensionable age; it is based on National Insurance Contributions  |



# Summary

## Aim

The aim of this project was to review and synthesise available evidence that could throw light on: why Black and Minority Ethnic (BME) customers are less satisfied with the Pension, Disability and Carers Service (PDCS); why BME individuals eligible for the PDCS benefits are less likely to apply for them; what interventions might be successful at raising levels of take-up and satisfaction with PDCS services; and what important gaps exist in research evidence to answer these questions.

## Background

There are marked differences in demographic and socioeconomic profiles between BME customers and the majority white population as well as between different BME groups.

**Older people:** In general, the demographic profiles of UK minority ethnic populations are younger than that of the white British majority. However, there are important differences between the minority ethnic groups, with some groups expecting rapidly growing numbers of older people in the next 10-20 years. The proportion of BME customers of The Pension Service (TPS) is likely to increase.

**People with limiting long-term illness and disability:** Several UK national data sources indicate substantial ethnic differences in the prevalence of activity-limiting long-term health conditions and disabilities that could potentially confer eligibility for Disability Living Allowance (DLA) or Attendance Allowance (AA). Levels of self-reported limiting illness and/or disability are markedly higher among people of Bangladeshi and Pakistani background compared to all other ethnic groups, from age 45 onwards. This difference continues in the over-65 group.

**Carers:** Those who spend large amounts of time caring are more likely to be eligible for Carer's Allowance (CA). Indian, Pakistani, Bangladeshi and other Asian groups were most likely to report spending 20 to 49 hours a week caring. Reports of providing 50 hours per week or more were most common among Bangladeshi

(2.4 per cent), Pakistani (2.4 per cent) as well as white Irish (2.5 per cent) and white British (2.2 per cent) groups.

Among those who are currently monitored at national level, Pakistanis and Bangladeshis are on average the worst-off ethnic groups in Britain across a range of markers including poverty and education. Other BME groups are generally worse off than the white majority. Poor socio-economic status is likely to play a strong role in long-term ill-health or disability that places BME individuals in purview of the PDCS.

There are differences in household structure between ethnic groups with implications for how income earning and caring responsibilities are met. For example, among Pakistani and Bangladeshi households there is a high rate of concurrence of child-caring and caring for a sick/disabled person.

**PDCS uptake and satisfaction:** Internal satisfaction surveys suggest that BME customers are less satisfied with TPS and Disability and Carers Service (DCS) services. There is limited evidence on uptake but the research available suggests that in relation to DLA, the uptake by BME groups is lower than would be expected.

## Method

A search of official government websites, academic databases and non-academic sources found little evidence directly relating to PDCS and BME satisfaction and uptake. We therefore drew on less direct evidence, including some from third sector organisations. There were a number of methodological issues:

### **a) Researching ethnic inequalities**

In the main, this report uses UK 2001 England and Wales Census categories and sub-categories for the BME population. However, such categories must not be presented as taken-for-granted, natural or neutral. Data presented for highly aggregated categories, such as 'Asian', 'black' or 'non-white' are particularly problematic; but even the more refined categories frequently conceal heterogeneity of circumstances and experiences.

Lack of involvement of minorities within the research process can mean a danger that a) topics of importance to BME groups are not researched and b) there is insensitive representation of these groups in research findings.

### **b) Satisfaction**

The evidence of lack of satisfaction among BME customers was the starting point of the study. Satisfaction surveys have been criticised but are currently regarded as an important tool with which to gauge the quality of statutory services. A limitation is that they tell us nothing about eligible non-claimants.

Satisfaction and uptake are probably closely tied; a high uptake by eligible claimants will correlate with satisfaction where a low or delayed uptake will correlate with

dissatisfaction. Among the evidence supporting this is the unhappiness expressed by claimants who had gone for long periods without a benefit before finding out their entitlement.

### **c) Quantity and quality of the available evidence**

Few studies look explicitly at the initiatives undertaken by the TPS or DCS in relation to ethnic inequality. There is also little that directly examines the experiences of BME customers of TPS or DCS. The report therefore draws upon less direct evidence; having said that, some themes emerging from this were strong and seemed likely to be relevant to PDCS.

There is a bias in the evidence base towards Asian communities, particularly Pakistanis. Some groups had little representation in the evidence; for example, Chinese and black Africans. There is also a bias towards small-scale, qualitative, community-based studies. Such studies can provide rich information about the perspectives and experiences of potential customers but are less useful at identifying the scale of particular problems/issues.

Finally, many studies have adopted an exclusive sampling design, or have not generated samples/undertaken analyses that have allowed comparative analysis across ethnic groups. Insofar as our concern is to identify factors that distinguish the experiences of minority ethnic people from the majority white British, many of the available studies are weak in this regard.

## **Main findings**

The evidence can be described in terms of factors affecting satisfaction and uptake; and these factors can be placed under three headings: personal factors; local factors; and PDCS system factors. These factors interrelate; for example, poor English language skills become a major issue only if the system has insufficient provision to deal with it.

### **Personal factors**

These are factors that in a sense belong to the individual customer, his or her characteristics. The evidence suggests a number of personal factors that might adversely affect BME satisfaction and uptake.

- 1 Poor English language skills: the mechanisms through which this appears to increase dissatisfaction include i) inadequate translation and interpretation services; ii) the use of terminology that is hard to translate or which has specific negative cultural resonance (particularly the term 'disability'); iii) difficulty for the customer in arguing a case for their benefit.
- 2 Level of awareness: BME customers, particularly new migrants are disadvantaged in terms of knowledge of the benefits system; there is also some evidence of false beliefs, particularly the belief that different parts of the health and welfare system will communicate with each other to ensure entitlements are given.



- 3 Attitudes and beliefs: there is little or no evidence of unease about claiming benefits from the state; some carers or those cared-for might resist hands-on care from strangers but that is a different matter. Some people dislike the terms 'carer' and 'disability' to an extent that could inhibit claims. And there is some evidence that families attempt to keep hidden the presence of disability in their family; this is something which could inhibit the use of local organisations for information about, for example, DLA. On the other hand, BME individuals might feel isolated from mainstream 'white' society in ways that make them distrustful or reluctant to approach statutory services.

### **Local factors**

These are factors in the local community and area, such as the extended family or local organisations.

- 1 Attitudes and beliefs: in some communities, women are expected to take multiple caring roles; women in this situation are likely to find the process of claiming onerous and may also be more likely to have other limiting factors, such as poor English language ability. Some in the local community express negative attitudes towards claiming some benefits, particularly those to do with disability, or towards disability itself.
- 2 The extended family: it is sometimes said that some BME individuals are able to draw on the resources of their extended family and that this could explain, for example, lower uptake of benefits. There is some evidence that extended families will help support those in need, particularly older people. However, in relation to disability the evidence is mixed, with some individuals complaining of little help but much 'moral policing' from relatives. Besides this, there is no evidence that extended family members would refuse financial benefits in helping care for a relative.
- 3 Local organisations: formal and informal networks give advice and help to individuals who are or might become PDCS customers. PDCS outreach work links with some of these organisations. There is evidence that some individuals prefer these to be their first point of contact, particularly where the organisations are BME-group focused. However, there are problems with such organisations. They are usually resource-poor and the quality of their help is variable. Their coverage is uneven; this means some individuals may have access to more help than others in dealing with the PDCS. Finally, they can promote dependency in an individual.

### **Factors in the PDCS and welfare system**

These are factors in the PDCS processes and procedures that could affect the satisfaction of BME customers. The issues highlighted can be placed under four headings.

- 1 Access: issues relating to access include:
  - difficulty in speaking English well enough to meet the needs of claiming, for example, using the telephone and presenting a case;
  - lack of professionals with specialist understanding, rendering some groups so-called 'hard-to-reach';
  - complexity of the system, which is an issue of particular importance to BME customers as opposed to others because their cases are more likely to have layers of complexity;
  - problems of eligibility for self-employed people disproportionately affect BME customers of TPS as such customers are more likely to be self-employed;
  - routes to welfare rights are ad hoc and uneven;
  - overreliance on translated written materials when there is limited literacy in a mother tongue;
  - some poor quality interpreting services.
- 2 Outreach: missed opportunities for health and social care professionals to inform people of their benefit entitlements.
- 3 Attitudes: stereotyping of BME groups as, for example, not taking up benefits because they prefer to 'look after their own'.
- 4 Monitoring: poor data on take up of Pension Credit by ethnicity; no data relating to take up of other PDCS benefits by ethnicity. This does not affect satisfaction directly but it makes it more difficult to pick up and tackle ethnicity-related issues.

The PDCS has an action plan addressing some of these issues and it is probably too early to judge the success of this.

## Conclusion

### **Why are BME customers less satisfied with the PDCS?**

A number of personal, local and system factors are implicated and interrelate. For example, English language is an important area of difficulty. The provision of good interpreters and translation services should help. However, this would not necessarily overcome the problems related to the complexity of the system and the need for individuals to make their case for benefits, something that requires high-level language skills. Another important issue is the presence of multiple problems for some individual customers; a woman with poor English skills and multiple caring roles will find the process of claiming especially difficult, for example.

### **Why are eligible BME individuals less likely to use the PDCS?**

Many of the personal, local and system factors implicated in lower satisfaction will also have their effect here. There is little evidence of individuals being averse to the general principle of claiming state benefits. However, perceptions of problems in the system can deter people from seeking to claim.

### **What interventions help?**

The PDCS has an action plan outlining a number of interventions. These have not yet been evaluated but on the face of it they should help with issues of access, attitudes, monitoring and outreach. However, insofar as the PDCS works through non-statutory organisations to do this there may be a concern about the uneven quality and coverage of such organisations. However, there are examples of other statutory organisations, such as Primary Care Trusts (PCTs), acting to improve benefit uptake; the PDCS might consider fostering this type of activity.

### **What are the gaps in the evidence?**

The evidence base specific to BME individuals as customers of the PDCS is small. What exists is dominated by evidence relating to Bangladeshi and Pakistani customers. However, these groups may be of most concern to the PDCS given the health and poverty profile. There is little evidence relating to the first step of the customer journey; that is, how the customer comes to approach the PDCS in the first place.

# 1 Introduction

## 1.1 Aim

The aim of this project was to review and synthesise evidence that could throw light on: why Black and Minority Ethnic (BME) customers are less satisfied with the Pension, Disability and Carers Service (PDCS); why BME individuals eligible for the PDCS benefits are less likely to apply for them; what interventions might be successful at raising levels of take-up and satisfaction with PDCS services; and what important gaps exist in research evidence to answer these questions.

The review was conducted by the Centre for Health and Social Care Research, Sheffield Hallam University (SHU), commissioned by the Department for Work and Pensions (DWP).

## 1.2 Report structure

Chapters 2 to 4 evaluate and synthesise the available evidence. Each deals with a set of factors that affect uptake of and satisfaction with the PDCS by BME individuals. Chapter 2 examines personal factors, such as how people self-identify (e.g. whether or not someone considers him/herself to be a 'carer'), past experiences of the benefit system, and facility in the English language; Chapter 3, local factors, such as prevailing norms and local resources, including community-based organisations; and Chapter 4, PDCS system factors, such as interpretation services.

The evidence itself is scanty with a predominance of material relating to South Asian groups. However, we disaggregate where possible and useful. The rest of this chapter sets out the methodology and background to this report.

## 1.3 Methodology

The relevant evidence is of a varied nature and quality, from formal quantitative and qualitative research through to unpublished local consultation and reports produced by lobby groups. Finding the evidence required several trawls using

different methods. An important and easily accessible source was research reports produced by the DWP itself and published on its website. For other academic papers we searched databases including ASSIA, Social Care Online, Sociological Abstracts and Web of Science. We used a comprehensive series of search terms beginning initially with terms specific to the PDCS services and then broadening the search terms to capture material relating to the customer groups of focus and BME populations (see Appendix A for details of the search strategy employed). In the main, we only included material published in or after 1997, which is when the New Labour Government came to power. Earlier material was felt unlikely to be useful since significant changes to policy and service provision would have occurred in the interim.

For the evidence from non-government and non-academic sources we reviewed websites and undertook email consultation with Third Sector organisations which had a remit to support either (i) older people, the disabled or carers and/or ii) BME groups.

We solicited material in two further ways: first, through email enquiry to the large distribution JiscMail lists: Minority-Ethnic-Health; Social Policy; European Social Policy; Global Social Policy; ICSP; SWAP; Ethnopolitics; Diasporas, Equality and Diversity; Service User Carer Group; Ageing; BSG; and second, through personal communication with leading researchers in the field and a review of their web-pages.

This evidence was filtered by hand and managed using the web-based bibliography tool, RefWorks. Appraisal and selection of the evidence was undertaken in two stages. The first involved ensuring that the evidence met basic criteria of relevance. If it did, it was entered into RefWorks and onto a spreadsheet. This evidence was then evaluated more closely for relevance with further selection taking place. The resulting evidence was entered onto new spreadsheets. This was then synthesized by the first author of this report using a framework developed during the process. The resulting report went through various stages of iteration, including a presentation to the PDCS. The evidence can be presented in tabular form as follows:

**Table 1.1 Summary of evidence in three categories**

|  |  |
|--|--|
| Directly concerns PDCS and BME customers               | (Age Concern. 2008, Barnard and Pettigrew 2003, Beatty, Fothergill and Platts-Flower 2009, Berthoud 2009, Bourn 2002, Britain 2009, Byrom, Knibbs and Dickman 2009, Comptroller and Auditor General. 2002, Disability Alliance 2003, DWP. 2009, Hancock <i>et al.</i> 2004, Hilton 2008, Hirst 1997, House of Commons Work and Pensions Committee. 2005, Howat, Norden and Garnett 2008, Kasparova 2007, Kelly, <i>et al.</i> 2004, Kotecha, <i>et al.</i> 2009, National Audit Office. 2006b Noble <i>et al.</i> 1997, Salway <i>et al.</i> 2007, Stockley, Lawless and Slade 2010)   |
| Indirect but close relevance to PDCS and BME customers | (Britain 2009, Afiya Trust. 2008, Ahmad 2001, Ahmad, Atkin and Jones 2002, Bywaters <i>et al.</i> 2003, Chamba 1999, Disability Rights Commission 2007, Downes 2006, Evandrou 2000b, Evandrou 2000a, Foundation 1994, Fraud and Error Strategy Division DWP. 2007, Greene, Pugh and Roberts 2008, Hall, <i>et al.</i> 2009, Harriss and Salway 2009, Hepworth 2005, Hepworth 2003, Hoskins and Smith 2002, Jones, Atkin and Ahmad 2001, Katbamna <i>et al.</i> 2001, Katbamna <i>et al.</i> 2002, Katbamna, Bhakta and Parker 2000, Katbamna and Matthews 2006, MECOPP 2006, MENCAP. 2006, Merrel and Kinsella 2005, Mills 2003, Moffatt and Mackintosh 2009, Moriarty 2008, National Audit Office. 2006a, National Black Carer and Carer Workers Network. 2009, Nazroo 2006, Netto 1996, Plastow and Thurston 2008, Platt 2003, Platt 2002, Platt <i>et al.</i> 2008, Powell 2001, Preston 2006b, Preston 2006a, Preston 2005 PRIAE. 2005, Salway, <i>et al.</i> 2007a, Somerville 2001, Suter 2001, Zahno and Rhule 2008)    |
| Indirect with some relevance to PDCS and BME customers | (Adamson and Donovan 2005, Alexander, Edwards and Temple 2007, Atkin and Chattoo 2007, Berthoud 1998, Bignall and Butt 2000, Boneham <i>et al.</i> 1997, Bowes and Sim 2006, Butt and O'Neil 2004, Chan, Cole and Bowpitt 2007, Chau 2008, Chung and Wong 2004, Crawford, <i>et al.</i> 2008, Department for Communities and Local Government. 2009, Department of Health Equalities and Human Rights Group. 2004, DWP. 2006, Fitzpatrick, Mold and Roberts 2005, Fry and Stark 1993, Gerrish <i>et al.</i> 2004, Gough and Hick 2009, Greasley and Small 2005, Grover 2007, Gunaratnam 2007, Harris 2003, Hirst 2000, Karliner <i>et al.</i> 2007, Karlson and Nazroo 2002, Lo <i>et al.</i> 2007, Magnet de Saissy 2009, Mold, Fitzpatrick and Roberts 2005, Nazroo 2003, ONS. 2004a, ONS. 2004b, ONS. 2003, Price 2006, Pudney <i>et al.</i> 2006, Purdam <i>et al.</i> 2008, Roberts 1998, Roberts and Harris 2002, Salway <i>et al.</i> 2009, Vernon 2002, Ward, Amas and Lagnado 2008, Young, Grundy and Kalogirou 2005) |

Overall, direct evidence examining satisfaction with and uptake of PDCS services by BME customers is scant and much of it is descriptive. Looking for reasons for lower satisfaction and uptake, therefore, requires taking into account less direct material. This fact alongside methodological issues results in a need for caution in interpretation. Furthermore, since there is little research that directly explores or evaluates elements of The Pension Service (TPS) or Disability and Carers Service (DCS) service provision; this report cannot produce specific recommendations for whether and how elements of current service delivery should be modified. Instead, we suggest that the findings presented here should be combined with evidence gleaned from internal scrutiny to identify appropriate responses within the context of: current priorities; funding constraints; and actions already implemented (but perhaps not yet established or evaluated) as part of PDCS's Race Equality Plan (which we discuss in Chapter 4). Finally, there are methodological issues inherent

in researching ethnicity. In Appendix F we set out some of these and how we respond to them in this report. We now move on to the background to the report.

## 1.4 Ethnic make-up of the potential customer base for PDCS services

This section provides an overview of the ethnic group profile of PDCS's potential customer population. It is based on background statistics derived from the 2001 Censuses and several national surveys, as well as drawing on some more detailed recent analyses.

### 1.4.1 Older people

In general, the demographic profiles of UK minority ethnic populations are younger than that of the white British majority. However, there are important differences between the minority ethnic groups, with some groups expecting rapidly growing numbers of older people in the next 10-20 years.

Katbamna and Matthews (2006) produced a demographic profile of BME older people in England for Age Concern using the data from the 2001 Census. It shows that in 2001, 97.1 per cent of the population aged 65 years and over reported belonging to a white ethnic group, with just two per cent of these people reporting white Irish or white Other ethnicity. Thus, the 2001 population aged 65 years plus was overwhelmingly of white British background. It is important to note, however, the significant geographical variation that exists. As with the geographical distribution of BME populations in general, we find larger numbers of minority older people in the South East, particularly London, the West Midlands, East Midlands and Yorkshire and the Humber. So, while for TPS at a national level, BME customers are a small minority, in particular localities they make up a far more significant proportion of the potential customer base.

Among the BME population of older people, those of Irish (155,295), other white (133,867) Indian (68,164) and black Caribbean (59,464) background were most prevalent (both because these are large ethnic groups and because their age profiles are older). There were much smaller numbers of Pakistani (29,436), Bangladeshi (8,918), black African (10,801) and Chinese (11,310) people aged 65 year and over in 2001.

2001 Census data indicate large variations in the gender distribution of people aged 65 years or over across ethnic groups. Katbamna found that women outnumbered men among the white (58 per cent), mixed (55 per cent) and Chinese (54 per cent) groups, reflecting the higher mortality rates among men (Katbamna and Matthews, 2006). In contrast, the proportions of men and women were roughly equal among people of Indian background, and there were fewer women than men among those of black Caribbean (48 per cent), black African (47 per cent), Pakistani (45 per cent) and particularly Bangladeshi (34 per cent) ethnic background; a product of past migration and settlement patterns.

Though currently people of BME background make up only a small proportion of the population aged 65 and over, this proportion will increase importantly in future years. Katbamna's (2006) population pyramids illustrated that the Indian, Chinese and black Caribbean groups have greater concentrations of people in the 40-59 years age-groups compared to the Bangladeshi, Pakistani and mixed groups whose age structures are far more youthful. The most recent Office for National Statistics (ONS) experimental population estimates from ONS for England for 2007 indicate that around 92 per cent of people aged 65+ are of white British background, with 2.2 per cent white Irish, 1.9 per cent white other, 1.2 per cent Indian, 0.99 per cent black Caribbean, 0.51 per cent Pakistani, 0.24 per cent black African, 0.21 per cent Chinese and 0.19 per cent Bangladeshi. Among those who are aged 80+, a little over 94 per cent are of white British background.<sup>1</sup>

#### **1.4.2 People with limiting long-term illness and disability**

Several UK national data sources indicate substantial ethnic differences in the prevalence of activity-limiting long-term health conditions and disabilities that could potentially confer eligibility for Disability Living Allowance (DLA) or Attendance Allowance (AA).

Analysis of the 2001 Census data for England and Wales conducted by ONS reveals that there were marked variations in self-reported rates of long-term illness or disability which restricted daily activities between different ethnic groups. After taking account of the different age structures of the groups, Pakistani and Bangladeshi men and women had the highest rates of disability. Rates were around 1.5 times higher than people of white British background. In contrast, Chinese men and women had the lowest rates (see Figure 1.1 and Tables 1.2 and 1.3).

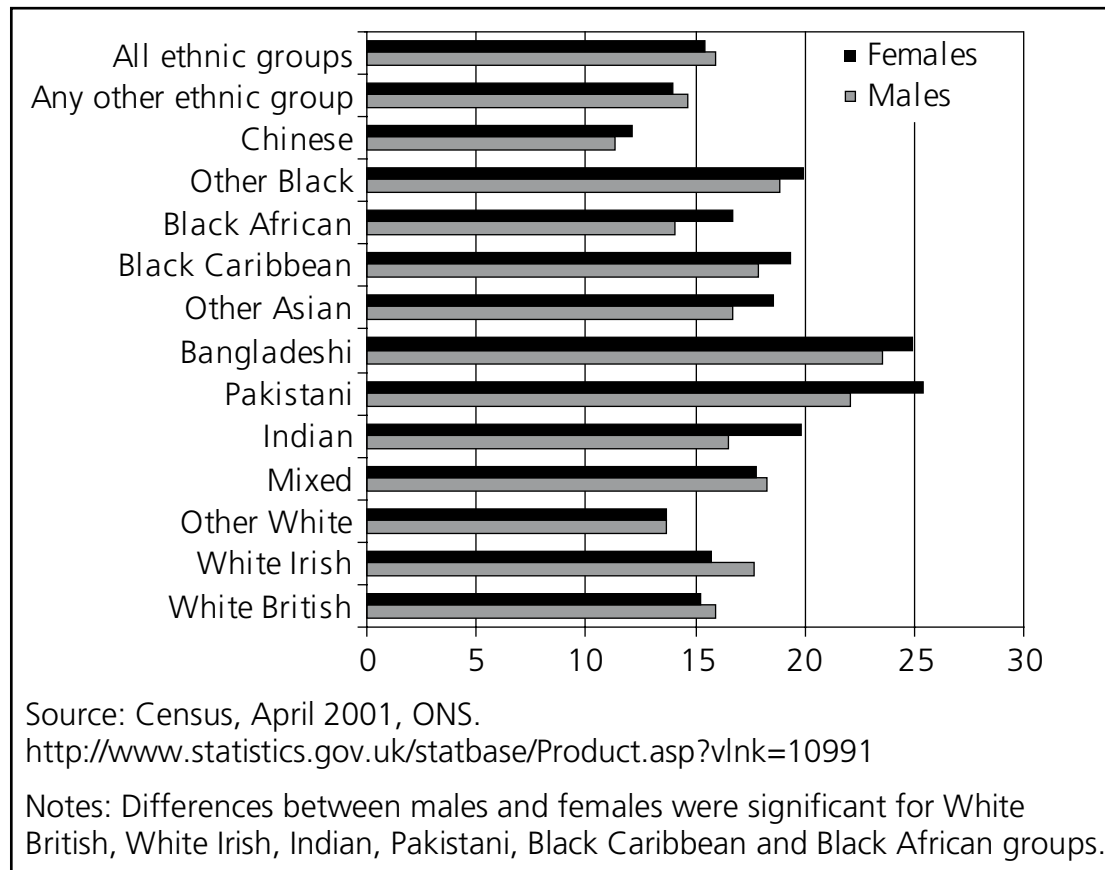
**People of working-age:** Looking more specifically at the working-age population, who would potentially be eligible for DLA, Salway *et al.* (2007a) used 12 pooled rounds of the quarterly Labour Force Survey (LFS) 2002-2005 to explore prevalence of disability among people of Pakistani, Bangladeshi, black African and white British ethnic background. The LFS included the questions '*Do you have any health problems or disabilities that you expect will last for more than a year?*' and '*Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out your normal day to day activities?*' which were combined to identify individuals with limiting longstanding illness or disability. The analyses showed that from age 40 onwards, among both men and women, there were higher rates of limiting illness/disability among both the Pakistani and Bangladeshi groups compared to the white British and black African groups. The Pakistani and Bangladeshi groups were also socio-economically disadvantaged, as noted above. There is likely to be a strong role played by socio-economic status, particularly among people of Pakistani and Bangladeshi background (Nazroo, 2006; Karlsen and Nazroo, 2002; Nazroo, 2003).

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<sup>1</sup> Percentages calculated from raw numbers provided on the ONS website: <http://www.statistics.gov.uk/hub/index.html>



**Figure 1.1 Age standardised rates of long-term illness or disability which restricts daily activities: by ethnic group and sex, April 2001, England and Wales (ONS. 2004a)**



**Table 1.2 Percentage of people reporting a long-term limiting illness or disability by sex, age-group and ethnic group, England and Wales 2001**

|                | White      |         |             |         | Asian or Asian British |             |             | Black or black British |         |             |  |
|----------------|------------|---------|-------------|---------|------------------------|-------------|-------------|------------------------|---------|-------------|--|
|                | British    | Irish   | Other white | Indian  | Pakistani              | Bangladeshi | Other Asian | Caribbean              | African | Other black |  |
| <b>Males</b>   |            |         |             |         |                        |             |             |                        |         |             |  |
| 16-49          | 9.9        | 11.8    | 6.9         | 7.7     | 11.2                   | 10.8        | 9.2         | 11.1                   | 7.2     | 12.1        |  |
| N              | 10,237,521 | 132,201 | 387,345     | 294,132 | 191,230                | 72,507      | 79,708      | 139,603                | 136,769 | 23,298      |  |
| 50-64          | 26.6       | 33.6    | 22.7        | 32.0    | 45.5                   | 55.7        | 29.4        | 33.4                   | 23.8    | 33.3        |  |
| N              | 4,125,581  | 83,354  | 82,965      | 65,910  | 26,856                 | 8,303       | 16,641      | 33,485                 | 15,576  | 2,323       |  |
| 65+            | 49.4       | 49.2    | 47.9        | 52.9    | 59.1                   | 65.2        | 50.2        | 50.8                   | 44.7    | 47.7        |  |
| N              | 3,246,944  | 67,662  | 61,436      | 34,077  | 16,555                 | 6,010       | 6,567       | 30,679                 | 5,795   | 1,502       |  |
| <b>Females</b> |            |         |             |         |                        |             |             |                        |         |             |  |
| 16-49          | 9.6        | 10.1    | 6.5         | 9.0     | 12.6                   | 11.7        | 10.0        | 10.7                   | 8.0     | 11.9        |  |
| N              | 10,299,484 | 137,730 | 448,789     | 303,447 | 190,886                | 73,372      | 62,074      | 173,797                | 154,515 | 28,519      |  |
| 50-64          | 25.7       | 29.2    | 22.9        | 40.9    | 53.2                   | 52.7        | 33.7        | 37.8                   | 32.0    | 36.8        |  |
| N              | 4,187,100  | 90,461  | 100,892     | 67,421  | 25,859                 | 9,635       | 13,650      | 42,287                 | 16,933  | 2,437       |  |
| 65+            | 53.0       | 49.1    | 51.4        | 65.1    | 66.5                   | 59.4        | 59.2        | 59.2                   | 52.8    | 54.5        |  |
| N              | 4,533,921  | 92,600  | 78,719      | 34,493  | 13,374                 | 3,058       | 5,926       | 29,183                 | 5,337   | 1,551       |  |

Continued

Table 1.2 Continued

|                | White and black Caribbean |                         | White and black African |                 | Mixed       |         | Chinese or other ethnic group |  |
|----------------|---------------------------|-------------------------|-------------------------|-----------------|-------------|---------|-------------------------------|--|
|                | White and black Caribbean | White and black African | White and black African | White and Asian | Other mixed | Chinese | Other ethnic group            |  |
| <b>Males</b>   |                           |                         |                         |                 |             |         |                               |  |
| 16-49          | 12.6                      | 11.5                    | 9.9                     | 10.7            | 3.8         | 7.3     |                               |  |
| N              | 41,209                    | 18,074                  | 41,067                  | 33,690          | 70,862      | 63,202  |                               |  |
| 50-64          | 33.1                      | 32.4                    | 29.0                    | 32.5            | 19.8        | 24.6    |                               |  |
| N              | 3,126                     | 1,734                   | 5,041                   | 4,628           | 11,672      | 9,969   |                               |  |
| 65+            | 48.4                      | 50.4                    | 44.5                    | 47.5            | 43.8        | 47.0    |                               |  |
| N              | 2,696                     | 794                     | 3,028                   | 2,288           | 5,414       | 2,756   |                               |  |
| <b>Females</b> |                           |                         |                         |                 |             |         |                               |  |
| 16-49          | 11.1                      | 10.4                    | 9.6                     | 9.5             | 4.6         | 6.0     |                               |  |
| N              | 47,408                    | 19,565                  | 41,070                  | 38,396          | 77,509      | 83,357  |                               |  |
| 50-64          | 35.7                      | 34.6                    | 29.0                    | 30.8            | 20.3        | 22.8    |                               |  |
| N              | 3,439                     | 1,881                   | 5,375                   | 5,360           | 13,681      | 14,495  |                               |  |
| 65+            | 53.1                      | 53.2                    | 48.5                    | 50.3            | 48.5        | 52.0    |                               |  |
| N              | 2,907                     | 978                     | 3,620                   | 3,057           | 6,221       | 3,626   |                               |  |

Source: Computed from raw figures provided by ONS at

<http://www.statistics.gov.uk/StatBase/Expodata/Spreadsheets/D7547.xls>

Notes: Ethnic group categories and age groups are those supplied by ONS.

**Table 1.3 Percentage of people reporting a limiting long-term illness or disability by age-group, sex and ethnic group, Scotland, 2001 (Census)**

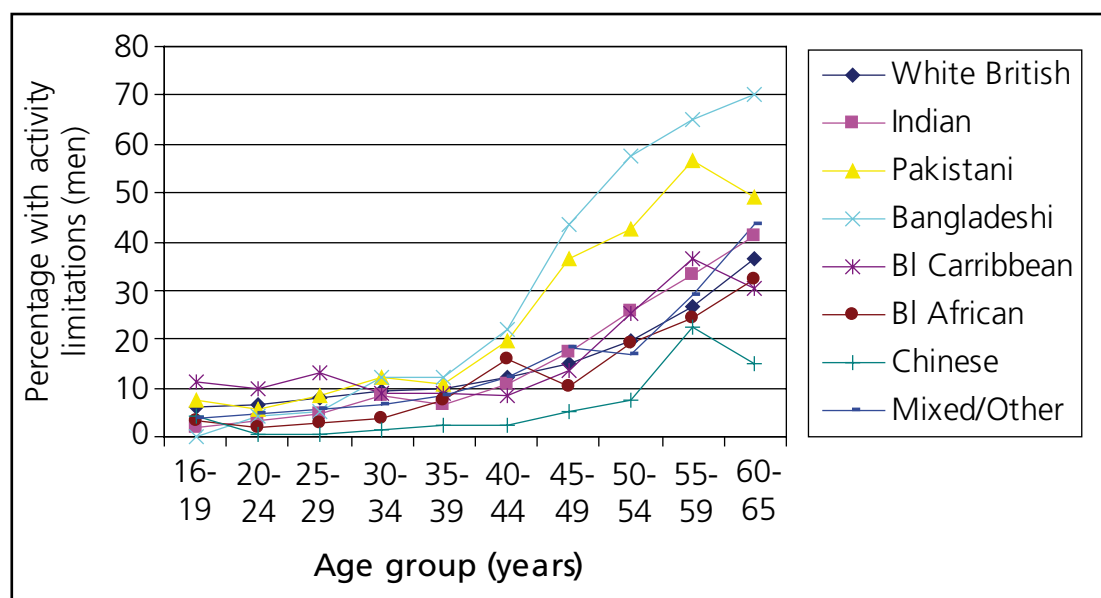
|                | White Scottish | Other white British | White Irish | Other white | Indian | Pakistani | Bangladeshi | Other South Asian | Chinese | Caribbean | African | Black Scottish or other black | Any mixed background |
|----------------|----------------|---------------------|-------------|-------------|--------|-----------|-------------|-------------------|---------|-----------|---------|-------------------------------|----------------------|
| <b>Males</b>   |                |                     |             |             |        |           |             |                   |         |           |         |                               |                      |
| 16-49          | 6.6            | 5.1                 | 5.5         | 4.7         | 4.8    | 7.9       | 6.0         | 4.8               | 3.2     | 7.1       | 5.7     | 10.8                          | 7.0                  |
| N              | 244,332        | 21,745              | 2,813       | 6,320       | 1,487  | 2,873     | 199         | 588               | 1,836   | 126       | 437     | 83                            | 1,227                |
| 25-34          | 10.1           | 6.9                 | 8.5         | 6.3         | 5.0    | 9.4       | 6.5         | 9.3               | 2.6     | 9.1       | 4.3     | 10.6                          | 14.3                 |
| N              | 287,486        | 29,515              | 3,877       | 8,059       | 1,729  | 2,885     | 216         | 616               | 1,475   | 175       | 704     | 94                            | 825                  |
| 35-59          | 19.3           | 13.9                | 21.1        | 13.9        | 15.3   | 24.6      | 17.6        | 17.4              | 11.1    | 16.7      | 10.3    | 24.4                          | 23.1                 |
| N              | 748,344        | 77,540              | 9,409       | 11,428      | 2,268  | 3,895     | 313         | 1,136             | 2,440   | 342       | 928     | 156                           | 919                  |
| 60-64          | 43.7           | 33.6                | 47.2        | 35.0        | 38.8   | 62.2      | 20.0        | 53.2              | 38.5    | 44.0      | 37.2    | 70.0                          | 52.0                 |
| N              | 110,658        | 10,040              | 1,529       | 1,080       | 278    | 537       | 25          | 62                | 226     | 25        | 43      | 10                            | 75                   |
| 65+            | 53.5           | 50.5                | 58.8        | 56.5        | 54.4   | 62.1      | -           | 58.3              | 48.7    | 48.5      | -       | -                             | 52.2                 |
| N              | 290,321        | 24,937              | 4,342       | 3,723       | 425    | 609       | 39          | 127               | 357     | 68        | 39      | 44                            | 249                  |
| <b>Females</b> |                |                     |             |             |        |           |             |                   |         |           |         |                               |                      |
| 16-49          | 6.1            | 5.1                 | 4.5         | 4.2         | 4.4    | 5.4       | 9.8         | 5.0               | 2.5     | 6.8       | 5.3     | 4.6                           | 6.7                  |
| N              | 239,356        | 22,711              | 3,008       | 7,299       | 1,294  | 2,978     | 163         | 459               | 1,731   | 132       | 432     | 87                            | 1,296                |
| 25-34          | 9.6            | 7.4                 | 6.1         | 5.0         | 7.0    | 10.3      | 5.9         | 10.3              | 4.2     | 8.0       | 5.5     | 13.8                          | 10.1                 |
| N              | 308,044        | 29,403              | 3,709       | 9,652       | 1,503  | 2,963     | 187         | 551               | 1,515   | 187       | 599     | 87                            | 943                  |
| 35-59          | 19.9           | 15.5                | 20.5        | 14.3        | 20.4   | 32.4      | 26.2        | 21.7              | 12.2    | 14.2      | 11.6    | 21.3                          | 21.2                 |
| N              | 785,113        | 76,218              | 9,178       | 12,972      | 2,039  | 3,733     | 191         | 720               | 2,615   | 324       | 640     | 155                           | 1,120                |
| 60-64          | 36.9           | 29.7                | 40.4        | 30.8        | 52.4   | 66.0      | -           | 39.6              | 39.5    | -         | -       | -                             | 44.4                 |
| N              | 123,013        | 9,982               | 1,831       | 1,274       | 189    | 329       | 15          | 53                | 167     | 28        | 25      | 14                            | 108                  |
| 65+            | 56.2           | 54.5                | 59.0        | 55.8        | 72.7   | 74.5      | -           | 52.5              | 57.5    | 47.4      | 52.7    | 60.9                          | 59.0                 |
| N              | 432,077        | 33,451              | 6,954       | 4,933       | 352    | 499       | 24          | 158               | 424     | 57        | 55      | 64                            | 354                  |

Source: Raw figures supplied by GRO(S) at \*\*\*\*\*, percentages computed by authors.

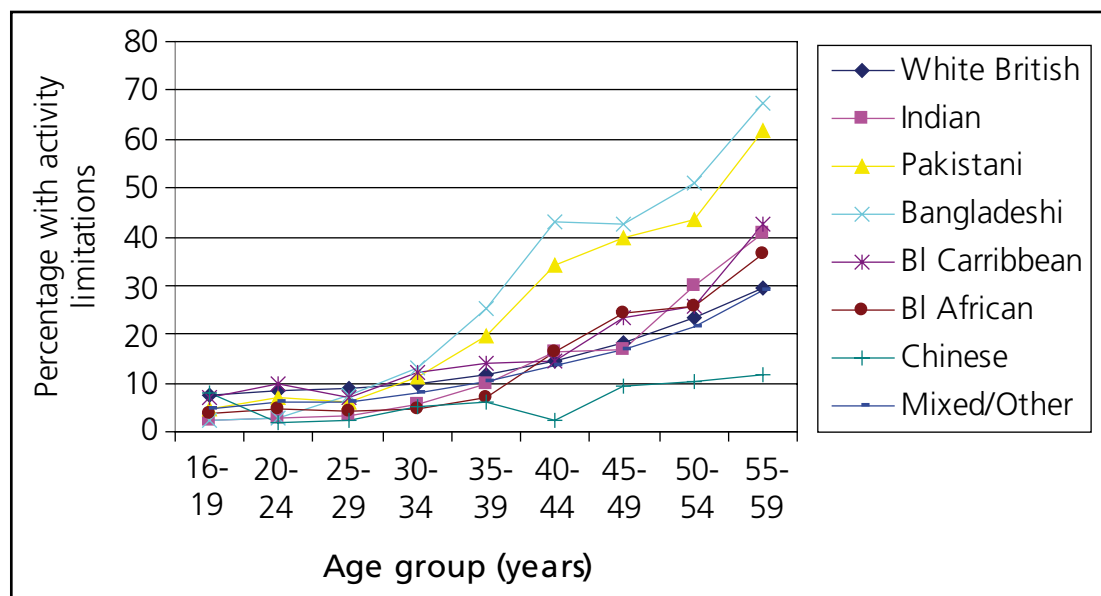
Notes: 1. Ethnic group categories and age groups are those supplied by GRO(S).

Harross and Salwa<sup>7</sup> (2009) extended these analyses to include other ethnic groups and we reproduce her figures below (Figure 1.2 and 1.3). Both figures confirm that the levels of limiting illness and/or disability are markedly higher among people of Bangladeshi and Pakistani background compared to all other ethnic groups, from age 45 onwards. Those of Chinese background tend to report lower levels than the other ethnic groups, particularly beyond age 40. Meanwhile, the rates reported among the white British, Indian, black African, black Caribbean and mixed/other group are broadly comparable across the age-range.

**Figure 1.2 Percentage of men reporting activity limiting illness or disability by ethnic group**



**Figure 1.3 Percentage of women reporting activity limiting illness or disability by ethnic group**



**Older people and disability:** Once over the age of 65 years, individuals who need help with personal care because they are physically or mentally disabled may be entitled to AA. As noted above, ethnic differences in the prevalence of limiting long-term ill-health and disability increase with age, and are most marked in older age-groups. Nazroo (2006) has commented on the extreme health disadvantage faced by older BME people. Katbamna *et al.*'s analysis of the 2001 Census data for England found marked ethnic differences in the proportion of people aged 65 years and over reporting limiting long-term illness: 49 per cent for white groups; 60 per cent for the broad category 'Asian or Asian British' and 54 per cent among the broad category 'black or black British' (Katbamna and Matthews, 2006). People of Chinese ethnic background, however, again stood out as having a lower likelihood of reporting limiting long-term illness than other groups, though such ill-health was still reported by more than 45 per cent of those aged 65 years or over.

Evandrou (2000b) used pooled data from the General Household Survey 1991-6, to explore health status among older people by ethnic group. However, given the low number of elderly men and women amongst some ethnic minority groups, such as Chinese and black Africans, her analysis was limited to examining the white majority population and those from the Irish, Indian, and black Caribbean groups and a combined 'Pakistani and Bangladeshi' group. Her analysis showed that among people aged 60 and over (the age-group used) not only did the Pakistani/Bangladeshi group stand out as having much higher levels of reported limiting illness than the white majority, but so too did the Indian group, amongst both men and women. Rates were similar among white British, Irish and black Caribbean groups.

It has been suggested that health-related return migration in which ill-health prevents migrants from returning to their countries of origin and concentrates ill-health among those who remain in destination countries may influence the wide ethnic inequalities at older ages. However, there is also likely to be a strong role played by poor socioeconomic status, particularly among people of Pakistani and Bangladeshi background (Nazroo, 2006).

### **1.4.3 Carers**

The 2001, Censuses in England, Wales, Scotland and Northern Ireland included the following question on caring: '*Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age?*' (Do not count anything that you do as part of your paid employment); with responses including 'No', 'Yes, 1-19 hours a week', 'Yes, 20-49 hours a week' and 'Yes, 50+ hours a week'.) This question alone does not allow us to identify people who would be eligible for Carer's Allowance (CA), since eligibility requires that a person be caring for 35 hours or more per week and that the cared-for person be in receipt of DLA, AA or Constant AA, among other conditions. Nevertheless, responses to this question do provide an indicative picture of the prevalence of caring responsibilities across the population.

ONS's routine analyses of these data by ethnic group (ONS, 2004a; ONS, 2004b) indicate that among all people, those from white British, white Irish and Indian backgrounds were the most likely to report providing unpaid care to relatives, friends or neighbours with longstanding illness and disability – around ten per cent. Those least likely to report caring were people from mixed (5.1 per cent), black African (5.6 per cent) and Chinese (5.8 per cent) backgrounds. These ethnic differentials partly reflect the older age structures of the white ethnic groups, as informal care is most likely to be provided by people aged 50 to 60 years.

The picture is, however, somewhat different if we examine those devoting large amounts of time to caring, that is the group that would more likely be eligible for CA. Indian, Pakistani, Bangladeshi and other Asian groups were most likely to report spending 20 to 49 hours a week caring (around 1.5 per cent among each). Meanwhile, reports of providing 50 hours per week or more were most common among Bangladeshi (2.4 per cent), Pakistani (2.4 per cent) as well as white Irish (2.5 per cent) and white British (2.2 per cent) groups.

Young *et al.* have conducted a more detailed analysis of caring using the Census data for England and Wales together with data from the ONS Longitudinal Study (Young, Grundy and Kalogirou, 2005). Using a definition of 'intensive caring' as those who reported 20 hours or more per week, and restricting the analysis to caregivers aged 16 and over and those living in private households, they found that there were approximately 130,000 caregivers from BME groups in England and Wales in April 2001, making up 7.8 per cent of all such carers. Out of these BME caregivers, nearly half were resident in London, 15 per cent lived in the West Midlands and approximately nine per cent each lived in the North West and Yorkshire and the Humber. In London as a whole, over 30 per cent of caregivers (57,090 individuals) were of ethnic minority background (8.4 per cent Indian, 6.4 per cent Bangladeshi/Pakistani<sup>2</sup>, four per cent black African, four per cent black Caribbean).

Across all regions, the prevalence of care-giving was highest in the Bangladeshi and Pakistani population, though there were some regional differences in prevalence of care-giving by ethnic group. There were also some differences by gender across the ethnic groups, with the Pakistani and Bangladeshi groups have the highest ratio of female to male care providers (2:1), compared to (1.4:1) for most of the other ethnic groups.

Young *et al.* (2005) were able to carry out regression analyses to control for background characteristics. These analyses confirmed that in all regions of England and Wales, those from Bangladeshi and Pakistani ethnic groups are far more likely than those from any other ethnic groups to provide 20 or more hours of care per week. Overall, compared to the majority white population, the combined category

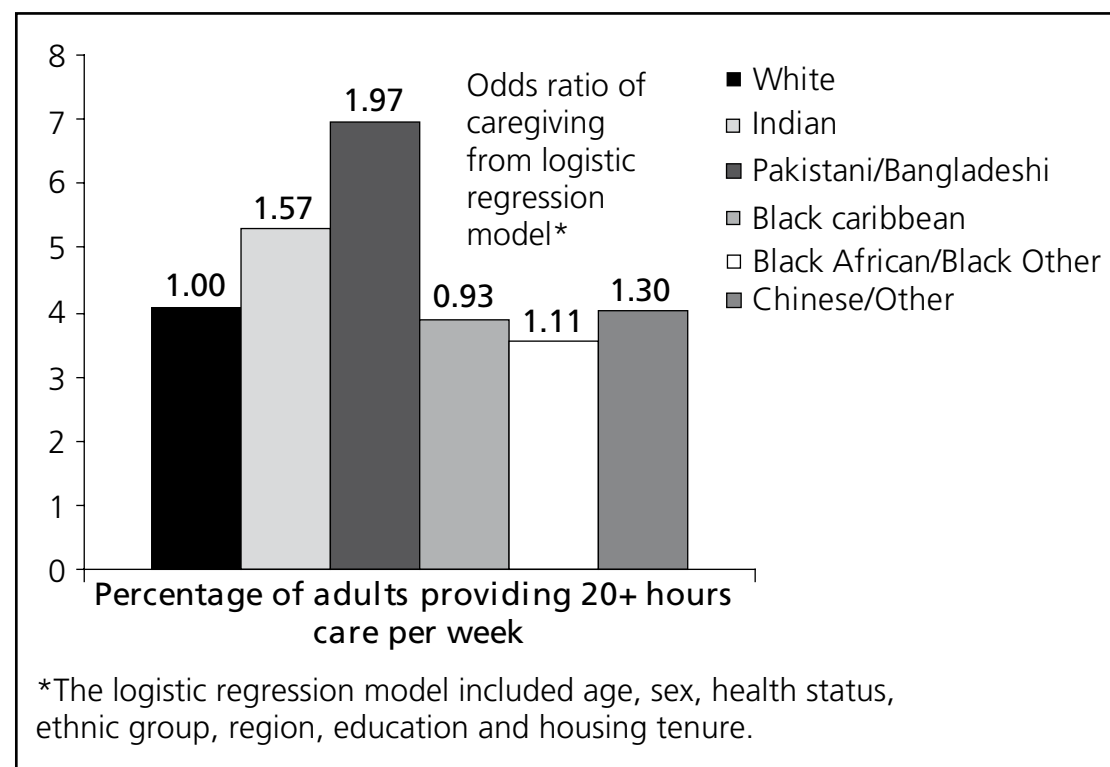
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<sup>2</sup> Young (2005) elected to use the combined category 'Bangladeshi or Pakistani' in their analyses, presumably to avoid small numbers in some of their regional-level analyses.

'Pakistani and Bangladeshi' had an odds ratio of caring of 1.97 (CI 1.80–2.15). The Indian population had 57 per cent higher odds of being a caregiver than whites (CI 1.43–1.72), while black Caribbean, black African and 'mixed' ethnic groups did not have significantly different odds of caregiving than the majority white group (see Figure 1.4). The high prevalence of caregiving among the Pakistani/Bangladeshi group tallies with the high level of incapacitating ill-health reported among people of these ethnic backgrounds.

**Figure 1.4 Percentage of adults aged 16 years+ reporting caregiving (20 hours+ per week) by ethnic group and odds ratios of such care-giving, Census 2001 England and Wales**

[Adapted from Young *et al.* (2005)]



Young *et al.*'s multivariate analyses also showed that caregiving was independently and positively associated with: poor health; lower socio-economic status and lower levels of education, suggesting a concentration of disadvantaged circumstances within particular households. The findings are consistent with those presented by Hirst (2000).

The UK Censuses identified 109,000 children under the age of 16 who were providing some informal care and that Indian, Bangladeshi and Pakistani children were most likely to be carers, around 1.5 per cent of each group (ONS, 2004a,b). While not eligible to claim CA themselves, their families might be entitled to supplementary support, and as we note below, such 'young carers' are likely to require particular assistance in accessing the benefits system.



## 1.5 Poverty

Take-up of benefits increases with the amount of entitlement (Pudney, 2006). Recent analyses also indicate that receipt of DLA is positively associated with indicators of lower socioeconomic status (Salway, 2007). These findings suggest that the perceived 'costs' of claiming from the PDCS in terms of time, effort, information needs, 'hassle' and stigma (Pudney, 2006; Platt, 2003) are weighed up against the potential monetary gains. Moreover, it seems likely that low-income households would face stronger incentives to claim even small amounts of benefit because of their greater relative contribution to household income. BME individuals and households are, on the whole, disadvantaged relative to the white British majority in terms of income and poverty levels.

Berthoud's (1998) analysis of data from the Fourth National Survey of Ethnic Minorities and the Family Resources Survey provided a detailed description of income sources and levels among minority ethnic households. While the profiles were diverse both within and between the groups, there was compelling evidence that Pakistanis and Bangladeshis '*were strikingly – shockingly – the worst off ethnic groups in Britain*' (p43). The black African group also tended to fare worse than black Caribbeans, who in turn had lower incomes than whites. The Indian group tended to earn as much as the white majority, but larger family sizes meant that overall prosperity was lower on average. The Chinese population were harder to characterise in terms of income levels due to small samples, though working Chinese families did have relatively high incomes.

Platt's recent report to the DWP has also highlighted the stark ethnic differentials in child poverty levels in the UK (Platt, 2009). She summarises the situation as follows:

*'All minority groups have higher rates of poverty than the average and compared to the white majority, according to the standard measure adopted by the Government for monitoring child poverty. With a fifth of children in poverty overall, black Caribbean and Indian children had rates of poverty of 26 and 27 per cent rising to 35 per cent for black African children. Over half of Pakistani and Bangladeshi children were in poverty according to most recent figures.'*

(p1)

Evandrou's (2000b) analysis of the General Household Survey (1991-6) focused on the socioeconomic status of older people and found significant differences both between and within minority ethnic groups. Evandrou reports that in her sample one-fifth of white and a quarter of Irish people aged 60 years or over were in the poorest 20 per cent of the income distribution compared with one-third black Caribbean, half Indian, and three-fifths Pakistani and Bangladeshi older people.

Evandrou also found that a lower proportion of minority ethnic older people were in receipt of a pension from their former employer than white or Irish elderly people and that while over three out of four of the older Pakistani/Bangladeshi group

and three in five of older black Caribbeans were in receipt of Income Support (IS) the comparable proportion for white older persons was one in three. Over half of Pakistani/Bangladeshi, two-fifths black Caribbean and a quarter of Irish older people were found to experience high or medium levels of deprivation.

Berthoud (1998) highlighted the differing access to pensions among older people across ethnic groups, with Indians having the best occupational pensions, but people of white and black Caribbean background being more likely to be in receipt of state pensions. The higher prevalence of socioeconomic need among BME groups would suggest a greater incentive to seek to claim support from PDCS than white British people, all other things being equal, though there is clearly important diversity between (as well as within) ethnic groups.

## 1.6 Household structure

As well as financial need and socioeconomic deprivation, incentives to claim benefit support from PDCS may be shaped by household structure. In particular, the coincidence of caring obligations towards children as well as elderly people may mean that some households face particular burdens of care. The availability of potential carers within the household (as well as nearby) may also affect people's propensity to look for state support when they become chronically ill/disabled, though people with limited networks of family support may also find themselves isolated from information and advice.

Platt *et al.* (2008) found differences in household structure between ethnic groups with important implications for how income earning and caring responsibilities could be met (and potentially the importance of additional support from the state). Table 1.1 is adapted from this study and illustrates that among households containing at least one person of working age with a long-term health condition, a large proportion of black African households were either single people (i.e. sick individuals with no immediate household members) or lone parents with children. Among the Pakistani and Bangladeshi households, almost half were couples with dependent children, implying the coincidence of child-caring and caring for a sick/disabled person. In contrast, white British households were more likely to be composed of a couple without dependent children. One report suggests that some rules relating to claiming, such as those forbidding the employment of a relative as a carer, are discriminatory against BME individuals in households where caring is undertaken by family members (Disability Rights Commission 2007).

**Table 1.4 Household composition by ethnic group: households containing one or more people of working age with a long-term health condition (per cent of households)**

|   | White British | Pakistani    | Bangladeshi | Black African |
|---|---------------|--------------|-------------|---------------|
| Single person                                 | 17.7          | 6.6          | 3.1         | 23.9          |
| Couple without children                       | 28.7          | 7.1          | 3.6         | 7.9           |
| Couple with dependent children                | 25.0          | 46.6         | 50.2        | 21.5          |
| Couple with non-dependent children only       | 11.3          | 6.2          | 4.5         | 1.6           |
| Lone parents with dependent children          | 6.5           | 9.5          | 10.5        | 25.7          |
| Lone parents with non-dependent children only | 4.4           | 2.4          | 2.3         | 4.8           |
| Complex (multi-family) households             | 6.4           | 21.7         | 25.8        | 14.5          |
| <i>Unweighted N (100%)</i>                    | <i>87,356</i> | <i>1,012</i> | <i>367</i>  | <i>606</i>    |

(Platt *et al.* 2008).

Notes: 'Complex households' include multiple family households, and couple or lone parent families where other people than (dependent and non-dependent) children are present. Same sex couples have been excluded due to small. Ethnic group is attributed to the household on the basis of the ethnicity of the household reference person.

The concentration of ill-health/disability within households is also worth highlighting. Harriss and Salway (2009) examined the proportion of households with working age members who had activity limiting illness or disability across ethnic groups. Overall, 39 per cent of Pakistani households (defined by ethnicity of household head) had at least one person with such an illness/disability, compared to 35 per cent of Bangladeshi households, 28 per cent of white British and Indian households, 23 per cent of black African households, 23 per cent of black Caribbean and just 11 per cent of Chinese households. However, a striking ten per cent of Pakistani and nine per cent of Bangladeshi households had more than one person with limiting illness/disability, compared to six per cent of Indian households, four per cent of white British, and lower percentages for the other ethnic groups.

## 1.7 PDCS uptake and satisfaction

### 1.7.1 Satisfaction

In the past, the TPS and DCS commissioned satisfaction surveys. The last one for TPS was conducted in 2007 (Howat 2008; see also Kelly *et al.* 2004), and for the DCS, in 2008 (Byrom, 2009). TPS survey was carried out through structured face-to-face interviews of a random sample of 2,392 customers; the DCS survey used postal questionnaires sent to 21,307 customers prompting a 40 per cent return rate. In both surveys, there is evidence of lower satisfaction from BME customers than those identified in the surveys as white. The DCS survey showed BME customers were less likely to speak highly of the service (51 per cent compared to 63 per cent), and were more likely have problems (25 per cent compared to 16 per cent); and of those with problems, BME customers were more likely to complain (34 per cent compared to 22 per cent). The TPS survey analyses showed that 21 per cent of non-white customers were fairly or very dissatisfied with the service against 12 per cent of white customers.

The PDCS now runs a quarterly satisfaction survey for all its customers called the Quarterly Satisfaction Monitor (QSM). This is based on around 1,500 phone interviews a quarter and includes collection of data on the respondents' ethnicity. Two waves have been completed and the report will be published once a full year's data are available.

### 1.7.2 Uptake

The PDCS has no figures for eligible non-take-up for benefits; there are considerable methodological difficulties in obtaining such figures. However, there is one exception: Pension Credit. The figures for 2007/08 showed take-up overall to be between 61 per cent and 70 per cent by caseload, an increase of about one per cent since 2006/07 and of nine per cent since 2003-2005 (Britain 2009) paragraph 112 using figures from research which the report does not cite. Breakdown by ethnicity of these figures was not done at the time. A subsequent report provides a breakdown based on the groupings 'white', 'mixed', 'Asian', 'black' and 'Other'.<sup>3</sup> This shows that the proportion of eligible non-recipients to eligible recipients is highest in the white group. Given that pensioner poverty is highest in non-white groups this is as would be expected other things being equal and is a favourable sign for PDCS policy in relation to uptake of benefits by BME customers. However, the authors of this report are cautious and the subsequent House of Commons report criticises the data (Britain 2009).

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<sup>3</sup> [http://research.dwp.gov.uk/asd/income\\_analysis/jun\\_2009/0708\\_PensionCredit.pdf](http://research.dwp.gov.uk/asd/income_analysis/jun_2009/0708_PensionCredit.pdf)

*'We are disappointed that the published data on Pension Credit take-up by ethnicity is of limited use. The shortcomings in the data make it impossible to confirm whether higher BME poverty rates are due to low take-up of Pension Credit. However, the extremely high levels of poverty suggest that this must be a factor. The Department needs to undertake further research in this area and identify what PDCS can do to improve the situation.'*

(Paragraph 130)

No data are available on uptake of other benefits by ethnicity from the DWP. Kasparova's (2007) study for the DWP explores the feasibility of modelling DLA uptake but to date we are unaware of DWP publication of the outcome of any such modelling. Attempts to assess the proportion of eligible people who are in receipt DLA, AA or CA are complicated by the high degree of subjectivity and uncertainty in the assessment processes. For example, DLA assessment requires self-evaluation of degree of impairment and DLA/AA decisions involve subjective judgement of these self-evaluations. A report for the Joseph Rowntree Foundation in 1999 *On the Edge* cites earlier research suggesting that BME customers were underrepresented in receipt of DLA and were less likely to receive the higher rate. However, this research is now dated and to our knowledge has not been replicated (Chamba, 1999).

To-date, just one paper has involved a quantitative exploration of PDCS benefit uptake across different ethnic groups. Salway (2007) used 12 pooled quarters of the quarterly LFS, from March 2002 to February 2005 to explore DLA receipt among people reporting limiting long-standing illness. The findings showed that amongst those reporting a long-term health condition, 13 per cent of men and 12 per cent of women reported receiving DLA. This rose to 19 per cent among those reporting activity limitations. Bangladeshis, especially men, had particularly low rates of receipt. This was surprising given the evidence that Bangladeshis experience the highest rates of poverty (Platt, 2003, 2002) and would therefore have the greatest incentives to claim any benefit entitlement. Multivariate analyses confirmed that DLA receipt was significantly lower amongst Bangladeshi, Pakistani and black African individuals than white British individuals, even having controlled for various confounding factors, including proxies for severity of health condition.

## 1.8 Conclusion

BME people make up a small proportion of potential customers for TPS although higher in particular areas of the UK; they are a proportionately larger group in relation to DCS. Furthermore, the high prevalence of financial need, particularly among some ethnic groups, suggests that, all other things being equal, minority ethnic groups would have strong incentives to access TPS or DCS benefits and that if received these benefits would make a significant contribution towards the welfare of these households. Despite this it seems that uptake of and satisfaction with the PDCS is lower amongst BME individuals; the rest of this report examines available evidence on the possible reasons.

## 2 Personal factors

### 2.1 Overview

This chapter examines the role of personal factors in the lower satisfaction with Pension, Disability and Carers Service (PDCS) services among Black and Minority Ethnic (BME) customers.

### 2.2 English language skills

Taking figures from the 2008 The Pension Service (TPS) customer survey, around six per cent of customers who approach the TPS directly, and eight per cent of those who use a customer representative,<sup>4</sup> have English for Speakers of Other Languages (ESOL) (Howat *et al.*, 2008). Of these, 25 per cent are white. Using broad ethnic categories, the survey's analysis shows that the proportion of customers who have English as second or other language varies by ethnicity: for Asian customers it is 75 per cent, for black customers, 20 per cent, and for the remaining broad category 'other' it is 50 per cent (Howat *et al.*, 2008, p.23). The figures for Disability and Carers Service (DCS) are unavailable. BME customers approaching the DCS will have a younger age profile than those accessing TPS and it seems likely, therefore, that they may have fewer problems with English language either because they are more likely to be UK-born or to have acquired English language skills, for instance via training or employment. Nonetheless, the fact that at least 20 per cent of BME customers of TPS report ESOL compared to just two per cent of white customers generally means that ESOL is a factor that differentiates white UK from BME customers of the TPS and seems likely to differentiate customers of the DCS to some extent.

Is there a close link between ESOL and dissatisfaction? In the Department for Work and Pension's (DWP's) own research reports difficulty with the English language has been noted for some time as a factor that may affect access to and satisfaction with services (Byrom, 2009; Kelly, 2004; Howat, 2008). However, the PDCS and other sections of the Department have undertaken several initiatives to

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<sup>4</sup> Customer representatives are non-professional aides who approach the service on behalf of the customer.

address the problem, including the use of professional interpretation services. It is therefore worth considering recent evidence.

The most recent satisfaction survey for TPS conducted in 2007 showed ESOL customers were less likely to report being 'very satisfied' with TPS overall (42 per cent against 58 per cent) (Howat, 2008). No equivalent figures are available from the DCS survey in 2008 (Byrom, 2009). Turning to academic evidence produced in 2008 and 2009, two studies explored the experiences of older people and other stakeholders of TPS (Moffatt, 2009; Plastow, 2008).<sup>5</sup> Both note poor English language ability as a factor adversely affecting the experience of BME customers. Their work is consistent with earlier findings from Merrell (2005) who looked at the experiences of Bangladeshi carers and Harris (2003) who looked at the experience of disabled refugees. All these reports discuss directly some of the experiences of carers, disabled people or older people in dealings relating to PDCS. Moriarty's Briefing Paper for the Race Equality Foundation shows that several reports link lack of English language competency to poorer service experiences, (Moriarty, 2008); and this is mirrored in grey literature (Zahno, 2008; Afiya, 2008). There is also evidence that having ESOL correlates with dissatisfaction in other areas of the DWP's service provision, particularly Jobcentre Plus (Hay, 2007; Nunn, 2009); and to dealings with the welfare state generally (Merrel, 2005). Thus, it seems likely that ESOL remains a factor in PDCS customer dissatisfaction. We turn next to possible reasons for this.

### 2.2.1 Adequacy of interpretation and translation services

BME users of health and social care services have had mixed experience of interpretation services, with some services being of poor quality and others being inadequate to meet demand so that users and practitioners fall back on the use of family members (Chamba, 1999; Gerrish, 2004). North American research in a health care context suggests that good quality professional interpreting services can raise quality of care for those with limited English proficiency to levels comparable with those who are proficient; equally important for our purposes is that satisfaction with care was also comparable between the two groups (Karliner, 2007).

An important objective of the PDCS Equality Plan is to help remove language barriers for customers (DWP, 2009 p.26-33). We discuss this further in Chapter 5 where we look at factors in the benefit system that affect satisfaction. In terms of customers with ESOL, however, the measures include:

- *'All of our business units continue to have an alternative communications team or nominated officers who are responsible for ensuring that customers receive products in alternative formats...'*
- *'A signposting leaflet in other languages has been published for our Pension customers who do not speak English...'*

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<sup>5</sup> Data Collection for the Moffat paper was 2005/6; Plastow's project took place 2008/09.

PDCS has also started to use the telephone interpreting service 'thebigword' as its main interpreting contractor.<sup>6</sup> One limitation of such a service, however, might be that professional interpreters are unable to act as advocates for the customer and, as such, not fully make up the gap between those with good and those with poor English language skills. This speculation is given weight by evidence from other areas which show a number of problems with interpretation and translation, such as the poorer quality by telephone and the limitations of interpreters acting as advocates (Department of Health Equalities and Human Rights Group 2004).

In terms of communication methods for people with ESOL, such customers seem particularly to dislike the use of telephone (Zahno, 2008). This might limit the usefulness of a telephone interpretation service. Written communications, such as leaflets, suffer from other weaknesses. The first is access (PRIAE 2005); people who are unaware of an entitlement to a benefit such as Disability Living Allowance (DLA) would not know to pick up information about it in the first place. Another access problem will exist for those whose daily lives do not include places where the leaflets may be placed or who do not use the internet. Outreach work is important in overcoming this problem (Aston, 2009). The second is literacy; some languages are not written and others are far more spoken than written; older people may not read even if the language is written; where this is the case, the written route is of limited use (Zahno, 2008).

### 2.2.2 Terminology

Some English terms do not translate directly or carry different resonance in other languages (that is, there might be a lack of conceptual equivalence). For example, many whom the PDCS would categorise as 'carer' and particularly 'young carer' would not recognise or would actively avoid the label themselves (Mills, 2003). The term 'disability' might also confuse or be differently interpreted by speakers of languages other than English (Salway, 2007; Chau, 2008). For many people it is a term associated only with learning disability. In unpublished material from the research undertaken by Harriss *et al.* (2009) we have:

*'Over and above generally high levels of ignorance, several Bangladeshi and Pakistani respondents held misconceptions about eligibility that related to an understanding of 'disability' referring only to individuals with severe physical or mental impairments (rather than incapacity associated with chronic illness); as do the translated terms 'pongota' (Bengali/Sylheti) and 'mazoor' (Urdu) used in promotional leaflets and conversation.*

*"No, Disability Living Allowance is a different thing. It's not for sick people. Disability is [for] those [who] are not clever enough, you know. Disability is those who can't move, or cannot speak, who [are] looked after [by] somebody else, then they get a disability allowance."*

(Bangladeshi male with long-term condition, 50-54 years)

<sup>6</sup> <http://www.thebigword.com/>



There are other areas of possible misinterpretation, as with this Pakistani woman with a long-term condition cited in Harriss (2009. p.30)

*'Social service people have registered me as 'registered blind'. I couldn't accept this mentally. I used to say that I'm not blind. I used to think that if they consider me a blind person they would stop my treatment and would not see me. And give up. But then the doctor told me that it is not that they would give up. Instead they would help me in getting the services. Then I agreed. But I used to feel very unusual when I used to think that I am registered blind...I used to hate this term.'*

### 2.2.3 Self-advocacy

In Hepworth's qualitative research with carers in Asian communities some participants spoke of the need to speak up for themselves in dealing with the PDCS (Hepworth, 2005). And Zahno (2008) makes a useful distinction between advice and advocacy; the first concerns information, the latter, helping someone achieve the outcome they want or would want if fully informed. Hepworth speculates that advanced English is required to communicate at this level required to negotiate access to statutory services including benefits; thus even those with fairly good ESOL might be disadvantaged when it comes to making points in discussion that expedite a claim. There is evidence in the grey literature to support this insofar as many organisations offer advocacy-style services for claiming benefits (Disability Alliance 2003). The following quotes from respondents in the Disability Alliance report illustrate the types of communication difficulties that arise:

*'Even though I speak, read and understand English, a lot of the time the forms use such language it's difficult to make sense. It is necessary to have someone explain it. Then...it's embarrassing to say you don't understand it...You are supposed to be grateful...'*

(Asian women carer aged 37)

*'...when you ask [for information] you are treated as if you are trying to get something you are not supposed to have.'*

(Disabled Asian woman who looks after disabled husband)

We discuss further the role of voluntary organisations in the next chapter. Our main point here is that speaking English as a second language, even quite well, can fall short of what is required to argue your case for a benefit. As a result, BME customers can find the benefit system complicated and stressful, and some express the feeling that they have been cheated, or that they are not trusted by the representatives of DWP, all factors that would no doubt increase dissatisfaction with the service on offer. One report from the DWP suggests that it is possible to 'overstate [the] importance' of language (Barnes, 2006, p.65). Vernon (2002) also questions the assumption that language is the main barrier to effective service provision and the related idea that interpreters and translated leaflets would solve all the problems for BME individuals. Qualitative research with ethnic minority

older people led the researchers to conclude that even those fluent in English struggled to obtain and understand information on entitlements. This suggests the complexity of the system itself is a barrier in addition to any language problems.

One other problem with self-advocacy is noted by Suter (2001); it is that some Asian people will give polite answers rather than complete ones to questions about their current situation; the effect is to reduce their eligibility as they play down problems. The same issue is reported in Platt *et al.*'s research (2008).

## 2.3 Level of awareness

There are at least two ways in which a lack of awareness may impact upon the uptake and satisfaction with services by BME customers: first, lack of knowledge of services and entitlements; and, second, false beliefs about such services. Most evidence relates to the first.

### 2.3.1 Lack of knowledge

The PDCS customer satisfaction surveys are concerned with current customers; there is no information concerning eligible non-claimants. Existing customers will have some knowledge of the PDCS but might lack knowledge of some of its processes and benefits. We could find no survey data investigating whether BME customers have less knowledge than white customers.

Lack of knowledge in BME customers nonetheless is a strong theme in the academic and grey literature (Merrel, 2005; Harris, 2003; Harriss, 2009; Moffatt, 2009; Barnard, 2003). Moffatt's interviews with older BME people (mainly Asian) suggested a low level of awareness of benefits generally (not just PDCS):

*'Most participants had little or no knowledge of the benefit system and what they might be entitled to. Those who did have some idea that there might be some financial assistance had no idea how to go about obtaining help.'*

(Moffatt, 2009 p.16)

Salway *et al.* (2007) reviewed a range of earlier studies before undertaking their own analyses of data from the Labour Force Survey (LFS) and new qualitative research with people reporting limiting long-term illness or disability. The quantitative data showed that Pakistani, Bangladeshi and black African individuals were less likely to be in receipt of DLA than white British respondents; and the qualitative research with comparable minority ethnic groups suggested lack of information to be one likely cause.

In the grey literature there is much to suggest lack of knowledge as a problem (Plastow, 2008; Disability Alliance 2003; Ahmad, 2002; Chamba, 1999; Chau, 2008; Suter, 2001; Afiya Trust, 2008; Mills, 2003; Butt, 2004; Harris, 2003; Greene, *et al.* 2008).

The extent to which lack of knowledge is a problem is likely to vary across and within ethnic groups, reflecting, for example, differences in length of time since migration and the degree of establishment of communities, networks in information exchange, and also occupational patterns. For instance, Moriarty (2008) notes that a relatively high proportion of black Caribbean women work in the public sector and have good knowledge of the system, although particularly the social care system rather than the benefits system. It also seems to be the case that levels of knowledge can vary greatly between local areas depending on networks of communication and presence of community based organisations. For instance, Harriss *et al.*'s (2009) qualitative fieldwork identified a group of Pakistani people who had benefited from a local network of information exchange and support resulting in good awareness of entitlements and several successful benefit claims, though this was not the case more generally for Pakistani people as reflected in the quantitative findings from national data.

### 2.3.2 False beliefs

From their interview evidence, Barnard and Pettigrew (2003) note that some older BME individuals believed benefits would be paid automatically if someone were entitled to them. And we have noted already that the terms 'disability' and 'carer' can be understood in different ways by some BME customers such that they wrongly believe the relevant benefits do not apply to them. Moffatt (2009) notes that the automatic entitlement assumption can be reinforced by a sense of incredulity in some customers that the various representatives of officialdom they have come across, such as GPs and social workers, have not told them of their entitlement and the need to claim. This is a theme also in Salway *et al.*'s study (2007a).

*'We didn't know nothing about disability allowance or anything like that, ... I didn't know nothing about the system. [The social worker] goes "Hasn't the income support, the social services ever interviewed you or asked your Mum about this, 'cause she's got that mental illness?", and I said "No, I didn't know nothing". She goes 'You've lost years and years of her disability allowance!'"*

(Pakistani female family member, 30-34 years) [p.61]

## 2.4 Attitudes and beliefs

We should be cautious in attributing behaviour to cultural attitudes or beliefs (see Appendix F). We should assume neither homogeneity nor immutability in, for example, a reluctance to accept outside help. We should also recognise the ways in which individual and structural socioeconomic factors can shape the options that are open to people. Nonetheless, it is worth considering whether there are attitudes and beliefs that are fairly culturally specific – or more firmly held among particular communities – and which could affect satisfaction with the PDCS. There are some highlighted in the evidence although the strength of that evidence varies.

It is worth remembering the dominance of evidence relating to Asian customers in this discussion.

### 2.4.1 Refusing help

One hypothesis in the literature is that some BME individuals might refuse or not seek PDCS help because of certain cultural attitudes. It is best to consider older people, the disabled and carers separately in relation to this.

We found little evidence that older BME people are averse to accepting pension services because of attitudes concerning charity or independence. One report suggests people view pension income as a return on their contribution, as their due, and for some that such income could enhance their independence and quality of life (Moffatt, 2009).

One exception to this is a survey of Chinese people in several UK locations which used semi-structured interviews and a postal survey (Chan, 2007). From this there is some evidence of hostility to the idea of the welfare state with a view that families and communities should be self-reliant. This attitude extended to pension services as well as DCS. In addition, academic research conducted by De Saissy (2009) with the elderly Chinese population in Northern Ireland also suggests that members of this community are more likely to access community based support groups rather than general services as they feel that these services are more culturally accessible.

The evidence is more complex in relation to disability and the services of the DCS. We noted earlier that the term 'disability' can be misunderstood as applying only to the learning disabled or people with severe disabilities from birth (rather than, for instance, ill-health related disability). There is also some academic evidence that individuals avoid the term being applied to themselves (Salway, 2007) since it can clash with people's self-identity.

*'They were all pushing me to do that [take DLA]. I say "I'm getting up. I will not stay in this bed like this"...They said "You stupid, you are mad". But I said, "Look all that I want, I want to be on my feet"...Although things were hard. But if I had compromised me. I'd feel it was a bit of compromising... Because I don't want to be accommodated into that disability thing. Funnily enough sometimes they [social workers] come here...they will use 'disabled'. I say "no, no, no, no! I'm not disabled!"'*

(Ghanaian woman with a long-term condition, 40-44 years)

*'People asked me to apply for it but I didn't (laughs) "Why not?" "Because I don't want to consider myself a disabled people, that's why".'*

(Pakistani woman with a long-term condition, 35-39 years)

While these attitudes were found among the majority white English respondents, the BME groups studied appeared to have them more strongly; Ghanaians were particularly averse to the label. The same study showed some people held negative

attitudes towards claiming DLA, associating it with, for example, scrounging, but these attitudes were expressed across all ethnic groups.

Similar attitudes have been found among carers of the disabled, particularly parents of disabled children who have been found to be reluctant to label their children as disabled or to want to hide them away. Ahmad (2002) found that the stigma of being deaf was pertinent for some ethnic groups, e.g. Pakistani Muslims. They drew the conclusion that deaf young people can therefore become alienated from their ethnic and religious communities. Purdam *et al.* (2008) found that disabled people from minority ethnic populations may be less likely to formally report that they have a disability than the white UK population and therefore be less likely to take up support services.

Other work by Katbamna (2000, 2006) and by Bywaters (2003) shows how religion can frame the views of Muslim parents of disabled children. Katbamna also notes that the community exerts a disapproving moral gaze in this respect. For example, disability in one child can result in poorer marriage prospects for siblings. However, Bywaters *et al.* (2003) found from their interviews with Bangladeshi parents of disabled children that there was little evidence that these views affected uptake of services or benefits (Bywaters 2003). However, such views could affect satisfaction with PDCS services insofar as individuals access these services through community organisations; we return to this point in the next chapter.

Moffatt's (2009) report of an intervention through which BME older people were informed of benefit entitlement, including DLA, showed all participants were able to claim additional benefit and that none of them refused to do so. This might suggest that any negative attitudes to claiming are weak, particularly where the need for help is greatest.

We noted above also that the term 'carer' is one that might confuse. It is also one to which some individuals may be averse and the term 'caregiver' is perceived by some BME people as being a more appropriate term to describe their own situation:

*'The word carer does not exist among many black socially excluded communities. Many people do not self-identify as carers. They perceive themselves as, daughter, son, mother or father who care for a relative who is sick or disabled.'*

(Powell 2001 p.21)

*'African-Caribbean carers have said that the word 'caregiver' is a term that they find is a closer description of their caring situation. Many people who provide care are in desperate need of outside support, even though they are perceived as reluctant to seek it.'*

(Powell 2001 p.21)

Another study suggests young male BME carers are reluctant to embrace the term 'carer' (Mills, 2003). There is also some evidence that Asian women chose not to accept help in the home and with direct personal care as they felt this was abdicating their own responsibility and obligations and might be perceived negatively by family or community members (Hepworth, 2005). MENCAP suggest that some Asian carers were uncomfortable with the idea of overnight respite care and thus missed out on services if only that was available (MENCAP, 2006) see also (Salway *et al.*, 2007). However, these findings do not necessarily equate to a preference for refusing state financial help – there is no evidence that such an attitude exists widely.

#### 2.4.2 Confidence and trust in PDCS services

Some grey literature suggests that some carers had little faith in statutory services but felt more comfortable going to voluntary services especially those within their own communities:

*'Carers from BME communities had poor knowledge of statutory sector provision of services and often expressed their lack of confidence in the statutory sector's ability to provide culturally relevant or appropriate services. The carers in our study were very reliant on voluntary sector agencies for service provision, which reinforced their perception that mainstream services were not designed for them.'*

(Afiya Trust, 2008:33)

Some research also found BME individuals reluctant to use a service that did not have a visible presence of individuals from the same BME group either as workers or service users (Powell, 2001; Afiya Trust, 2008). This sense of isolation from mainstream services was an important theme in Salway *et al.* (2007):

*'...many respondents in both the Pakistani and Bangladeshi groups expressed feelings of alienation and exclusion from 'mainstream' society and services, factors that reinforced their tendency to rely on 'our own people', despite the variable ability of this strategy to meet needs.'*

[In answer to a question about whether receiving support from charities or organisations]

*'I am searching for such groups, really I want to know how these other organisations work, but I have not been able to find out much. I got a leaflet, but where they are located and what they do I have not been able to find out. I have asked friends or people that I know. I try to find out if there are any Bengali people among them, who could help, but I have not been able to find anybody.'*

(Bangladeshi male family member, 40-44 years) [p.62]

Finally, individuals develop attitudes to PDCS as a result of past experiences that colour their current behaviour and beliefs. One such experience is a perception of apparent capriciousness in PDCS decisions:

*'I am a support worker and I'd say I fill in around four to five of these DLA forms a week. And you know, I never know when I send them off which ones are going to be successful.'*

(Pakistani female advice worker, 35-39 years, group discussion)  
(Harriss 2009 p.62)

Further, the experience of rejection discourages some from seeking other benefits or support.

*'When I was ill and unable to move my friends told me that I should claim disability allowance. But I did ask for it and I was turned down. There are other things my friend tells me that I can claim. Some money for home repairs and things like that. That I haven't. And there are other things that I do not know about. To be honest, I am just not interested to get into this, because I am never lucky, and I do not want unnecessary hassle.'*

(Bangladeshi female with long-term condition, 35-39 years)

## 2.5 Conclusion

Poor English language skills seem closely tied to lower satisfaction and take up of PDCS benefits and services by BME individuals. It is worth noting that Moriarty's Briefing Paper for the Race Equality Foundation is a synthesis of research evidence relating to the health and social care experience of BME older people. It reports that fluency in English varies across different BME groups with lower levels tending to be found with Chinese, Vietnamese, Pakistani, Bangladeshi and Somali older people. Given that Asian customers appear to be disproportionately represented in research into BME customers of the PDCS, it is possible that the English-language problem is given undue significance when research findings are applied generically to BME groups. Nonetheless, the proportion of those with limited English language skills is notably higher than white-UK customers across all BME groups. Furthermore, these are the groups with higher levels of poverty, illness and caring which put them in purview of the PDCS.

However, the problems this gives rise to might not be resolved completely through good telephone interpretation services. If engagement with the PDCS requires (self-) advocacy then a telephone interpretation service is likely to be insufficient to address the disadvantage experienced by those with limited English language skills. It seems likely that simplification of services and the provision of face-to-face specialist support and advocacy will also be required. Having said that, people's familiarity and comfort with phone technology is likely to have changed in recent years; recent email traffic on JISMAIL ethnicity forums suggest that telephone-based services are becoming more acceptable to BME groups.

Lack of knowledge of benefits is certainly marked as an issue for many BME customers and particularly so for those with poor English.

The available evidence does not suggest that cultural attitudes are a significant factor affecting uptake or satisfaction with services, though an expressed desire for 'culturally sensitive' services is commonly mentioned (see Chapter 3 for more on this issue). However, two terms in the PDCS name, carer and disability, have been found to be associated with some confusion or resistance among some BME individuals.





# 3 Local factors

## 3.1 Overview

This chapter examines the role of local factors in affecting satisfaction with Pension, Disability and Carers Service (PDCS) services among Black and Minority Ethnic (BME) people. We divide these into two broad categories: attitudes and beliefs, and resources.

## 3.2 Attitudes and beliefs

The attitudes and beliefs of individuals sit within wider community attitudes and beliefs. In this section we examine these and how they might affect customer satisfaction with PDCS. It is worth repeating the caveats that, first, the evidence is weighted towards Asian groups, particularly Bangladeshi and Pakistani, and, second, that we should not assume homogeneity or stasis in attitudes within a community. Indeed, the term 'community' is a problematic one (Alexander, Edwards and Temple, 2007).

### 3.2.1 Role expectation

There is some evidence that women in the Bangladeshi and Pakistani groups take and are expected to take a caring role in relation to children, the sick and older people (Moffatt, 2009; Suter, 2001; Salway, 2007). In the previous chapter we reported finding no evidence that this expectation was allied to a desire to take the caring role without financial support from the state. But the role expectation might be important in a different way. Some of these women will have multiple caring roles and are thus likely to be potential or actual PDCS customers. They are also one of the groups to have relatively high rates of problems such as limited English language ability and access to resources such as the internet (Moffatt, 2009). In other words, it seems this group of PDCS customers has a high level of need and entitlement combined with a low chance of accessing it satisfactorily.

### 3.2.2 Negative social attitudes

As we reported in the previous chapter, individuals tend to view pensions and benefits in old age as their due. With disability and the related benefits the picture is different. We have seen already that individuals within particular BME groups, such as Ghanaians, might be strongly averse to being labelled as disabled. A report for Department for Work and Pensions (DWP) suggested that people are more comfortable identifying themselves by ethnicity than by disability or sexuality; and, in particular, some Asian disabled people suffered stigma within the community and might be shut away by the family (Molloy, 2003). There is also evidence of negative attitudes to mental health and disability within the Chinese community (Chung, 2004; Lo, 2007).

Katbamna (2000) interviewed and held focus groups with 59 female carers, 27 male carers and eight people being cared for; participants were from four South Asian BME groups: Bangladeshi Muslims, Pakistani Muslims, Gujarati Hindus and Punjabi Sikhs. Respondents in this study reported negative attitudes to disability from, for example, their relatives. The researchers point out that whilst some of these took a particular cultural construction, such as blaming disability on misdemeanours in a past life, others seemed generic, such as blaming wrongdoing by the pregnant woman or saying that the disability must have a genetic origin in the other side of the family. Nonetheless, this type of generic attitude can have more force in some communities. This is illustrated by research with Bangladeshi and Pakistani groups suggesting that the disability of one family member affects the life chances, such as marriage prospects, of others (Harriss, 2009). These and other negative attitudes and behaviours served to isolate carers and disabled people and to encourage concealment, particularly of disabled children.

A slightly different way in which a community's negative attitudes to disability might affect an individual's interaction with PDCS is through expression of the idea that benefit claimants are scrounging and should be working instead. In Salway *et al.*'s (2007) research, all four ethnic groups examined (including white English) expressed negative attitudes to the receipt of welfare benefits, mentioning words such as scrounging, lazy and degraded; and this attitude affected claiming for Disability Living Allowance (DLA) even though this benefit is not dependent upon employment status.

Negative attitudes held within someone's local ethnic community might also affect his or her willingness to engage with local groups. Much outreach work appears to depend on such groups but if a family is concealing the presence or extent of a disability in a family member they may be reluctant to use groups composed of people they know. We return to this point presently.

The expression of negative views towards benefit claimants other than pensioners seems quite widespread across both BME and the majority communities. There is no evidence to suggest it is higher in BME groups with the possible exception of those of Chinese origin (Chan, 2007; Magnet de Saissy, 2009). As such, it would

seem unlikely to be a specific factor in the dissatisfaction of BME groups with PDCS. We should add two cautions, however.

First, it is possible that the negative views could be expressed more strongly against particular groups and, therefore, affect them disproportionately. This might be the case with, for example, asylum seekers and refugees (Harris, 2003; Roberts, 2002) or with some BME groups more than others. Some evidence suggests that Asian customers of the PDCS may experience more difficulty with the service, particularly in terms of additional investigation undertaken in processing their claims (Disability Alliance, 2003; Afiya Trust, 2008). Whilst this could be due to accidentally discriminatory factors, such as relying on documentation that such customers find harder to get, it could also reflect a wider negative social attitude to such claimants (Atkin, 2007).

Second, the negative views might affect some groups more strongly than others in terms of their feelings and behaviour. If a particular BME group has an uneasy relationship with other areas of Government, such as the Home Office, then a campaign against fraud by the DWP might make individuals from that group reluctant to engage with the PDCS for fear of opening themselves up to wholesale investigation. There is no specific evidence of this. It would require, for example, an investigation of benefit take-up by ethnic groups exposed and not exposed to such campaigns. There is some evidence, though, of fear amongst BME customers.

*'I get so frightened that I will say something wrong and lose my benefit'*  
Asian woman, aged 82 [p.17].'

(Disability Alliance, 2003)

*'I worry about asking for information in case I get into trouble – when you ask you are treated as if you are trying to get something you are not supposed to have. Do they think because I am Asian I shouldn't be getting help?'* Disabled Asian woman who looks after her disabled husband [p.18].'

(Disability Alliance, 2003)

To some extent the above two points are factors in the PDCS system, which is the focus of the next chapter. However, the more general point is that negative attitudes held locally will add to people's unease about PDCS. One result is that they may be reluctant to approach local organisations (see discussion below).

Turning from barriers to resources, there are two possible local resources of importance to BME customers of the PDCS: the extended family and community groups.

### 3.3 Extended family

The idea that BME individuals are likely to be supported by extended family networks obviating the need for state support is refuted by available evidence (Katbamna, 2004; Adamson, 2005; Downes, 2006; Chamba, 1999; National

Audit Office, 2002; Comptroller and Auditor General, 2002). Adamson's research suggests that services need to be open to supporting carers who are generally perceived, due to cultural factors, as 'doing it themselves' and therefore, not in need of statutory services including PDCS benefits:

*'It is likely that carers expressing their caring role in terms of their ethnicity have been misinterpreted as 'looking after their own' and goes some way in explaining the perpetuation of this stereotype of caring being culturally specific. This should not, therefore, deter appropriate service provision to support carers from minority groups.'*

(Adamson 2005, p48)

Even if it were true that BME individuals were more likely to receive support from the extended family it is not obvious that this would lead to less claiming of benefits. Indeed, the opposite is likely given higher poverty amongst BME groups alongside evidence that poverty is generally a spur to uptake of discretionary benefits (DWP, 2006; Pudney, 2009; Hancock, 2004).

Arising from several sources is a suggestion that communities are changing (Katbamna, 2006; Plastow, 2008). Families are moving apart and older people are increasingly likely to be living alone. If this is so then, as Asian communities age, the older individuals will be looking to the State for support more than to family networks.

Turning to younger disabled people and their carers, some evidence suggests that Bangladeshi and Pakistani extended families provide little help and can even be unhelpful. There may be an expectation that children and older people require care; disability, though, is sometimes a stigma.

*'Relatives offered little practical help but much moral policing of the parental performance...'*

(Katbamna, 2000 p.23).

The same authors refer back to another study (Chamba, 1999). This also showed that South Asian parents generally received little family help in caring for a disabled child. Alongside this, however, a desire to conceal the disabled child might be a barrier to seeking the relevant benefit.

Although most of the evidence available relates to Asian individuals, Chau's review of evidence on the health experiences of the Chinese population in the UK also raised doubts about the view that the community meets its own needs (Chau, 2008). In terms of health care provision, the Chinese population is relatively dispersed in the UK and those needing care can be isolated. Salway *et al.*'s study included a focus on black Africans in the quantitative work and Ghanaians in the qualitative component (in addition to the Asian groups). This study also suggested that material and practical support was often not forthcoming from family members and that black African people, particularly women, were particularly isolated (Salway *et al.*, 2007a).

Overall, participants in qualitative studies commonly report little by way of help from the family in relation to disability. Downes (2006) found that 'more than half of the BME carers interviewed did not have access to informal support from friends or family'. It seems unlikely that BME disabled people and their carers are choosing not to access PDCS benefits or other support because their extended family is adequately meeting their support needs. For care of older people there is evidence of extended family support although it is inconsistent and may be on the wane in Asian families; even where it exists it is not inconsistent with claiming benefits. Some family structures might negatively affect uptake of relevant benefits; if an older person, particularly an older woman, is supported within an extended family and does not have a separate income, that person might not be aware or think of the possibility of claiming for him or herself (Moffatt, 2009).

### 3.4 Local organisations

Local organisations and groups were a strong theme in the literature reviewed. The organisations can be categorised in various ways. First, some are national, others local. For example, *Help the Aged* is a national charity; *Sheffield 50+*, local. Second, some have a wide focus, others narrow. For example, *Citizens Advice Bureau* is aimed at a wide range of people; *Sheffield Somali Association* has a more specific remit. Third, some may be focused on a condition, others on a BME group, others a religion and yet others on a combination: *National Autistic Society*; *Pakistan Community Advice Centre*; *Northern Sikhs* and so on. The help such organisations offer that is relevant to the PDCS includes: advice; help with form filling; translation; interpretation; and provision of advocacy. The organisations rely on volunteers although some have paid employees also.

The Pension Service (TPS) and Disability and Carers Service (DCS) information on the 'Directgov' internet sites offer as 'useful contacts' a number of national charities.<sup>7</sup> The greatest number of links is to charities associated with the disabled. We found none that were BME specific or specific to a locality, although many of the organisations themselves will have local offices. Some of the larger organisations, such as Help the Aged, have specific BME advisors.

Non-statutory organisations play a central role in liaising between statutory services and individuals in some BME communities (Barnard, 2003). One study explicitly cited them as a better source of help than the extended family (Somerville, 2001). The organisations were said to have a role in liaison between services and the individual as advocates (Powell, 2001; Afiya Trust, 2008; National Black Carer and Carer Workers Network, 2009; Somerville, 2001) outreach workers (Zahno, 2008) and interpreters. From the perspective of improving satisfaction with PDCS services, it seems likely that these organisations have an important role to play. There is also evidence that organisations with a specific BME focus are attractive to BME individuals (Barnard and Pettigrew, 2003). Given these points it seems

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<sup>7</sup> <http://www.dwp.gov.uk/index.shtml>

clear that TPS and DCS are right to use such community organisations in their outreach work. There are at least two issues that PDCS should consider in doing so, however. These are equity, and quality and accountability. The point concerning equity is not something we found in our survey of evidence but arises from our own critical reflection; the issue of quality and accountability has been highlighted in published research reports.

### **3.4.1 Equity**

There is a range of organisations; and the issues, BME populations and geographic areas they cover are uneven. A disabled Somali in Sheffield might be fairly well served in terms of available help because of the presence of a relatively large and well-established Somali community there. Were the same person to live in a city without such a community it is unlikely he would have a similar level of support. Similarly, older people in general are fairly well served by charitable organisations in applying for a benefit such as pension credit; by contrast, it is likely that parents of children with unusual disabilities will have less obvious sources of community help in, for example, applying for DLA. In other words, BME individuals' support from community organisations will depend on: the size of their BME community both nationally and locally; and the nature of the problem that puts them in PDCS purview.

Could some claimants gain an unfair advantage from community organisations? For example, in applying for DLA it could make a difference to the rate awarded if the PDCS know you are up for several hours a night looking after the disabled person. But someone who is in this position might not make it clear in their application unless an informed individual checks it and asks them. If such help is available only to some individuals then it sets up inequality in the PDCS processes; something likely to affect both satisfaction and uptake.

Of course, small-scale organisations cannot help everyone. For charities, there is nothing wrong with helping one person and not another. However, the PDCS has a remit to cover all relevant claimants and potential claimants. In doing this it needs to be aware of uneven levels of support available to claimants and aim to make the best available to all. This might influence who it works through and how it commissions services from the third sector.

### **3.4.2 Quality and accountability**

We did not find precise information on how customers and potential customers come into contact with TPS and DCS. However, one route will be top-down; PDCS liaise with a national charity which, through its local offices, liaises with a local BME-specific group. This is one way in which outreach operates. However, a typical customer journey might be quite different. In this, the individual hears about a local organisation by word-of-mouth. For example, having given birth to a disabled child a woman might be given the details of a small local group. She would contact that group but what happens next will presumably be

hit-and-miss; much of the literature points to poor financing and uneven levels of knowledge and service from these groups (Barnard and Pettigrew, 2003, Moffatt and Mackintosh, 2009).

Local groups have limited accountability for the advice and help they give. A small local organisation might lack the knowledge to support a claimant (Barnard, 2003; Disability Alliance, 2003). Charitable and third sector organisations generally have resource shortages and may be unable to do, for example, outreach and translation work (Greene *et al.*, 2008; Bowes, 2006). Insofar as a BME group is marginalised in society the likelihood is that local organisations relating to that group will also be marginalised.

Some older people in one study expressed concern about the standards of confidentiality in community organisations (Barnard and Pettigrew, 2003, p.109). We found no research examining the standards of confidentiality within third sector organisations; and most of the respondents in Barnard and Pettigrew's research expressed trust. However, concern about confidentiality could be important where there is some stigma attached to the benefit claimant, as with mental health problems or childhood disability (Greene *et al.*, 2008; Chung, 2004).

This finding links to a further issue; that using intermediary bodies promotes dependency in the claimant. A claimant using a third organisation in dealing with the PDCS depends upon it to some degree. To some extent, this runs counter to the general imperative to empower claimants (as discussed in the Freud Report) (Grover, 2007).

### 3.5 Conclusion

There are local factors that help and hinder the process of claiming benefits from the PDCS. Our review suggests some inconsistency between the way many BME customers use local organisations and the way PDCS uses them; there are also differences in the groups used. The picture we have developed at this stage is that the PDCS uses organisations in a top-down way, usually partnering with fairly generic and national charities. These charities will liaise with some local groups as well as their own local offices. By contrast, individuals will tend to go to local groups first, often with a BME focus; these local groups are likely to be resource and information poor and may not be the ones that have the top-down link with PDCS. There are many positive aspects to local and national charities and they are the first port of call for many individuals in need. However, the PDCS needs to be aware of problems that arise from these organisations being uneven in their coverage of claimants and in the quality of advice they provide; they might also be below acceptable standard in terms of confidentiality.





# 4 Factors in the PDCS system

## 4.1 Overview

This chapter reviews the evidence on factors in the Pension, Disability and Carers Service (PDCS) system, in its processes and procedures, which may affect satisfaction with PDCS services. As before, evidence has also been drawn from areas beyond PDCS where it seems relevant and casts light on the factors likely to affect satisfaction with PDCS. We begin with an examination of three reports that critique the statutory services to the disabled, the elderly and carers, and which make a series of recommendations. Although The Pension Service (TPS) and Disability and Carers Service (DCS) are not always the targets of these recommendations, many of the recommendations are or were relevant.

## 4.2 Three reports

*Out of Sight* is a 2003 publication from Disability Alliance (2003). It reports a review of evidence from a range of sources including the Office for National Statistics (ONS), the Benefits Agency and the charity *Disability Alliance* itself. The latter commissioned a qualitative study of the experiences of Asian women carers and people with disabilities. The rationale for the focus on Asian women is that they seem to be the most distant from the benefits service in terms of factors such as language. However, the study takes evidence from around 70 organisations that have long-term experience of supporting Black and Minority Ethnic (BME) groups and its findings appear to be applicable more broadly than to Asian women alone. The report's disability focus means it is not concerned with TPS.

*Delivery of Services to Ethnic Minority Customers* is a report of the 2004/05 sessions of the House of Commons Work and Pension Committee (2005). It seems to be the most recent report of this body directly addressing the needs of BME customers. The Committee sought out memoranda from a range of sources, took oral evidence and visited the offices of TPS and Jobcentre Plus in Wolverhampton.

As this shows, the Committee's focus was Department for Work and Pensions (DWP) work as a whole. Consequently, the findings and recommendations of the report do not all relate to the DCS and TPS. It is worth noting that in Parliamentary committees, the word 'evidence' is used idiomatically and includes anecdotal material that would not count as evidence in a scientific context.

*Delivering Benefits and Services to Black and Minority Ethnic Older People* is a report of a research study commissioned by the DWP and published in 2003 (Barnard 2003). Its focus is the uptake of the Minimum Income Guarantee (MIG: now merged into Pension Credit) among older BME people. Its method is case studies based on seven BME groups in particular localities.

The summaries of recommendations from two of these reports are included in Appendices C and D; the DWP's own report is readily available online. Below, however, we summarise the recommendations relevant to the PDCS under four themes: access, outreach, attitudes and monitoring. As these reports were all written before 2006, we also draw on evidence up to that date from other sources where they make supporting or additional points. Once we have looked at the four themes, we turn to the action that has since been taken by the PDCS and to evidence of whether this has addressed some of the problems and issues highlighted before 2006.

**Access:** two problems with access seem to recur in these reports and other data. The first is the complexity of the system. The reports make several recommendations towards simplification, such as shorter forms and the use of a single-entry point for benefits (the latter is sometimes termed a 'one-stop shop'). It might be thought that complexity does not particularly count against BME customers; white UK customers suffer from it too. However, the higher prevalence of other factors within some BME groups, such as poor English, low educational qualification and the complexity of household structures (Section 1.6), does, in effect, make it a BME issue. The second problem with access is English as a second language. The reports make recommendations for the improvement of interpreting services and of translated materials. One recommendation is that a language marker on relevant websites should immediately direct non-English speakers to help. To date, we note that in relation to PDCS sites this is only true for Welsh speakers, the result of the Welsh Language Act. Other recommendations include the use of non-written formats for non-literate customers; the provision of language-specific help-lines; and the offer of home visits for those who need them.

**Outreach:** the three reports suggest that statutory services should actively seek out their clients and customers rather than attend only to those who show up; some of the neediest are unable or unlikely to do so. *Out of Sight* recommends marketing campaigns that target areas or populations of apparently poor uptake of benefit with the aim of triggering people to think 'Am I entitled?' and then show them how to find out and get effective help in claiming. This should be in a wide range of formats, as stated above, and through forums such as community radio. Language-specific help-lines are suggested. Another action that has proved

helpful is the use of benefit clinics with facilities for interpretation into commonly spoken local languages and of home visiting for some customers unable to get to such clinics. Finally, it is recommended that benefit information to individuals is provided automatically following certain triggers; thus, for example, a GP would provide information about DLA to someone who seems likely to meet the criteria.

Attitudes: Out of Sight states that BME customers of DCS:

*'Have to confront attitudes, behaviour and institutional obstructions which at best, demonstrate lack of understanding or are based on erroneous assumptions. At worst, they are actively racially hostile and discriminatory.'*

(p.5)

It cites evidence from a survey undertaken by Disability Alliance and other research about, amongst other things, the length of time taken to process claims from Asian customers, that such customers were more likely to be asked to provide further evidence, and that they were more likely to face investigation. Barnard and Pettigrew's research into TPS found that attitudes of staff to older BME people were problematic; for example, in the African case study, the report states:

*'Some older people reported that unsatisfactory experiences of claiming benefits, and of other statutory services, had made them reluctant to claim benefits.'*

(p.94)

This point concerning other statutory services is worth emphasising; even were there no attitudinal problems towards BME customers from PDCS staff, those customers might have experiences with other services that strain their interaction with the PDCS (Hepworth, 2005).

Hepworth (2005) also discusses professionalism. He notes that the carers' desire for informal, friendly and consistent relationships with professionals, particularly social workers, conflicted with the system's rules and norms regarding professionalism. The House of Commons report (which concerns the DWP as a whole) notes a lack of BME staff members in the DWP and recommends strategies to address this; something mentioned also in the other two reports. And all reports talk of the need for cultural sensitivity with, for example, caution regarding the use of male staff to deal with female Asian customers. The reports make recommendations such as that the Department should undertake assessments of race equality and cultural awareness training.

Finally, although the House of Commons report mentions hostility in the benefits-claiming process (p.34) it cites no evidence for it. A PRIAE (2005) study involving in-depth interviews with 390 BME elders in the UK, published in 2005, found that 77 had witnessed racism from providers of health and social care. However, the DWP is not specifically mentioned in relation to this. As such, any charge of hostility or racism amongst DWP staff appears unfounded. However, the PRIAE report suggests there is some stereotyping by DWP staff that undermines the

service to BME customers; the chief example given is the assumption that BME families prefer to look after their own rather than seek help.

**Monitoring:** A theme in all three reports is the lack of data on ethnicity in relation to DWP or PDCS. The recommendations in relation to monitoring include ethnic monitoring at entry and exit point for all benefits and services.

### 4.3 PDCS responses

A good source of information for ascertaining relevant PDCS action is its race, disability and gender equality scheme. The most recent Action Plan for the race equality scheme was published in a 2009 progress report (DWP 2009 – Appendix E of this document). It lists objectives and with each of these it has a set of actions, timescales, intended outcomes and a progress update. Some single actions are claimed to meet many objectives but it addresses the following:

- **Access:** the contracting of ‘thebigword’ telephone interpretation service in 2007<sup>8</sup>; all business units to have an alternative communications team or nominated officers responsible for ensuring that customers receive products in alternative formats; a signposting leaflet in other languages.
- **Outreach:** an outreach programme that includes BME groups as a particular focus.<sup>9</sup>
- **Attitudes:** a mystery shopper service which assesses how staff deal with calls from customers whose first language is not English; published guidance on how to deal with such customers and how to access ‘thebigword’; regular equality awareness training; a bespoke visiting service for customers who need it; Race and Islamic awareness training; staff to take part in the Community 5000 initiative.<sup>10</sup>
- **Monitoring:** specific monitoring of the satisfaction of BME customers and of uptake in the case of Pension Credit; equality impact assessment of new initiatives and policies.

As is apparent from the last point, Pension Credit is in some ways a special case. At time of writing, it is the only benefit for which PDCS has uptake targets. Maximising take-up of Pension Credit is also a priority in light of the high levels of poverty among ethnic minority older people. A recent report by Age Concern (2008) cites data from DWP showing that pensioner poverty levels are highest among older people from BME groups, with 32 per cent of older people from

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<sup>8</sup> <http://thebigwordopi.com/case-studies.aspx>

<sup>9</sup> We did not find much detail on the outreach programme but it seemed as though the events were generic but BME groups were a focus in the sense that events were held at, for example, Mosques or BME community centres.

<sup>10</sup> This aims for staff to give 5,000 hours of work to voluntary and community organisations.

Asian groups, 29 per cent from black ethnic groups and 30 per cent from Chinese or other ethnic groups in poverty compared to 17 per cent of older people from white groups. This may explain why there is a greater reliance among Asian and black pensioners on means-tested benefits with nearly half (46 per cent) of Asian and black pensioners in receipt of means-tested benefits, compared to less than one-third (31 per cent) of white pensioners (Stevenson and Sanchez, 2008).<sup>11</sup> The same report also showed that, on average, incomes from means-tested benefits only make up five per cent of the total income of white pensioner households, whereas they account for around 15 per cent of the total income of Asian and black pensioner households.

There is evidence that take-up of Pension Credit is lower than average among ethnic minority older people. Statistical modelling undertaken for the NAO (2006) report<sup>12</sup> indicates that, controlling for other factors, take up of Pension Credit is lower in areas with large minority ethnic populations. As there is also clear evidence of a higher risk of poverty amongst ethnic minority pensioners, as shown earlier, this is a finding that appears to call for further investigation and action.

#### 4.4 Evidence since 2006

Thus, the PDCS has set out initiatives to tackle the problems identified in reports such as those cited in the previous section, published in 2003-2005. We turn now to evidence since then concerning the satisfaction of BME customers.

We saw earlier, in Section 1.6 the direct and indirect evidence in BME groups for lower satisfaction with PDCS services. Most of this has been published since 2006 although in some cases the data was generated in an earlier period (e.g. Salway's 2007 report includes data from the Labour Force Survey (LFS) 2002-2005). The DCS and TPS satisfaction surveys that show lower levels of BME customer satisfaction were published and based on data collected post 2006 (Byrom, 2009; Howat, 2008). The DCS survey found that indicators of satisfaction for BME customers were, if anything, slightly worse than the previous survey two years earlier; the TPS survey does not make a comparison with the previous survey and both it and the earlier TPS survey have comments about small numbers of BME customers making the figures unreliable.

The most recent DWP-commissioned research (Stockley, 2010) is a small qualitative study of 30 PDCS customers of whom 11 were identified as 'non-white' although it is unclear whether this was a self-attribution by the respondents or whether

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<sup>11</sup> Data sourced from DWP's 2007 Pensioners' Incomes Series, based on 2003-2006 averages.

<sup>12</sup> In a separate technical report (NAO, 2006b) the authors also note that the correlation between local authorities with large minority ethnic populations and lower take-up of Pension Credit are not particularly strong so the results must be treated with care.

they were put into this category on the basis of self-identifying as, for example, Asian. The sample takes in three main groups: non-white, those with English for Speakers of Other Languages (ESOL), and those with long-term illness or disability. This small sample has several sub-groups as any one recipient could be in one, two or three of the main groups. One of the aims of the study was to find the potential causes of lower overall satisfaction in all three groups but in this respect the study is disappointing perhaps in part due to the methods and sampling used. Many of the problems identified by customers with ESOL and BME customers are similar to those that had been identified in the earlier studies. Two points stand out, however. The first is that satisfaction with treatment by TPS staff seems good; second, that those with English good enough not to require an interpreter nonetheless found that accent was often an issue, with TPS staff struggling to understand them.

In the wider academic and grey literature there is little direct research post-2006 focusing solely on BME customers of the TPS or DCS and their BME customers. One exception was produced by a team including one of the authors of this report (Harriss, 2009). However, there is indirect evidence of relevance that discusses or describes the experiences of BME older people, carers or disabled people with the health and social care system of which interaction with the PDCS is a part. In this literature, there appears to be some frustration that little progress had been made (Afiya Trust, 2008). Using our same four themes as headings, the criticisms include:

**Access:**

- difficulty in speaking English well enough to meet the needs of claiming, for example, using the telephone and presenting a case;
  - lack of professionals with specialist understanding, rendering some groups so-called 'hard-to-reach' (Afiya Trust, 2008; Salway, 2007);
  - complexity of the system, which is an issue of particular importance to BME customers as opposed to others because their cases are more likely to have layers of complexity (Age Concern, 2008; Plastow, 2008);
  - problems of eligibility for self-employed people disproportionately affect BME customers of TPS as such customers are more likely to be self-employed (Britain 2009);
  - routes to welfare rights are ad hoc and uneven (Moffatt, 2009);
  - overreliance on translated written materials when there is limited literacy in a mother tongue (Plastow 2008; Zahno 2008);
  - some poor quality interpreting services (Moriarty, 2008; Plastow, 2008).
- **Outreach:** missed opportunities for health and social care professionals to inform people of their benefit entitlements (Moffatt, 2009) (plus some evidence of successful examples of schemes promoting this (Hoskins and Smith, 2002) as well as evidence of reluctance on the part of some professionals to do this (Greasley and Small, 2005); insufficient outreach to and specific work with BME groups (National Black Carer and Carer Workers Network, 2009);

- **Attitudes:** stereotyping of BME groups as, for example, not taking up benefits because they prefer to look after their own (Ward, 2008; Greene *et al.*, 2008; MENCAP, 2006; Ward, 2008);
- **Monitoring:** poor data on take up of Pension Credit by ethnicity (see Chapter 1 of this report and Britain (2009)); no data relating to take up of other PDCS benefits by ethnicity (Harriss, 2009).

## 4.5 Conclusion

The factors in the PDCS system that are cited as causes of lower satisfaction and uptake by BME customers can be categorised under the headings of access, outreach, attitudes and monitoring. The PDCS action plan and other documents outline actions the department plans to undertake or has undertaken to tackle these issues. The effects of these are not known at this stage.





## 5 Conclusion

This chapter draws together the points from the previous three in order to address the questions which began this report. These are: why Black and Minority Ethnic (BME) customers are less satisfied with the Pension, Disability and Carers Service (PDCS); why BME individuals eligible for the PDCS benefits are less likely to apply for them; what interventions might be successful at raising levels of take up and satisfaction with PDCS services; and what important gaps exist in research evidence to answer these questions. Where this chapter summarises the claims made in the previous chapters and the reader is referred back to earlier sections of the report for the evidence supporting the claims.

### 5.1 Why less satisfied?

#### 5.1.1 Personal factors

Across all BME groups, speaking English as a second or other language is present to a higher degree than the white UK population. It is particularly high in groups such as Bangladeshi women. There is evidence that good quality interpreting services can overcome many of the problems arising from this factor. However, the evidence suggests that for customers of the PDCS, problems remain.

- Those with English for Speakers of Other Languages (ESOL) struggle to use the phone for complex communication; but this is widely used in The Pension Service (TPS) and Disability and Carers Service (DCS) communication with customers (see Section 2.2.1).

- There are problems also with provision of written materials in translation either on the web or as leaflets. One is that it is difficult to ensure that all clients have access to them; the more isolated individuals may not go to public locations where the materials are placed and they may not have access to the internet (Section 3.3). A second problem is that of the signposting towards such translated material since weblinks are often in English and are sometimes hidden away and customers often have to proactively seek out leaflets or request translated versions rather than these being prominently on display in offices. This means that such materials are likely only to be accessible to those who already have reasonable English proficiency (see Section 2.2.1). Third, it is difficult to make provision for customers who speak languages less commonly used in the UK, such as the three main Chinese dialects. Finally, where a language is primarily spoken rather than written, providing written materials is of limited use; there is a preference often for word-of-mouth communication particularly amongst those who are elderly who may be illiterate in their own language anyway (see Section 2.2.1).
- Some terms are problematic in translation: the terms 'disability' is difficult to translate into some languages and the translated terms used carry negative connotations not present in English; similarly 'carer' may have negative connotations (see Section 2.2.2).
- A further problem relates to self-advocacy. Claiming a benefit often involves making your case to the statutory bodies. This requires advanced language skills that will be beyond many customers with ESOL as well as some native English speakers (see Section 2.2.3).

A second area of difficulty for BME customers relates to lack of knowledge of the system and some false beliefs about it. Those not born in the UK in particular are less likely to know and understand the benefits available, the processes to go through and the names for the various documents required in making a claim. It might be thought that this factor would affect uptake rather than satisfaction. However, some of the dissatisfaction with PDCS is caused by customers coming to the benefit route by chance and then realising, for example, that they have gone years without a benefit they were entitled to (see Sections 2.3.2 and 4.4). The most important false belief sometimes attributed to BME individuals is that they believe they will automatically be given benefits they are entitled to. We found no evidence for this but we did find evidence that people thought the welfare state would be joined up such that, for example, your GP would alert you to entitlement to Disability Living Allowance (DLA). Some individuals were incredulous that this did not happen (see Section 2.3.2). However, some Primary Care Trust (PCTs) have taken part in schemes of opportunistic benefit advice (see Section 2.3.2)

### **5.1.2 Local factors**

Local groups and community-based organisations often play an important role in alerting people to benefit entitlement and helping them with their claims.

However, this help can be uneven and is of variable quality (see Sections 3.4.1 and 3.4.2). As well as this, there are some individuals who are reluctant to use them (see Sections 3.2.2 and 3.4.2). We speculated that this might be so particularly where the individuals have concerns about confidentiality. For example, where a family wishes to keep secret the presence of a disabled child (see Section 3.2.2), the family carer may be reluctant to discuss DLA with a local organisation that has volunteers that he or she knows.

### **5.1.3 PDCS system factors**

We categorised the factors in the system affecting satisfaction under the headings of access, outreach, attitudes and monitoring.

- Access – The TPS and DCS have complex systems for benefit claims and monitoring of claims. This complexity is a problem for many customers but might affect BME customers disproportionately due to at least three factors (see Sections 1.6, 2.3, 4.2 and 4.4). First, some customers, particularly those born abroad, will have difficulty getting the necessary documentation. Second, customers with possible entitlement to several benefits will face even higher levels of complexity. There is evidence that, for example, many Bangladeshi and Pakistani women have multiple carer roles. As such, they or those they care for might be entitled to several benefits; but these same women will have busy lives and are more likely to have English language problems; they might also have less access to relevant help and information. As such, they are disadvantaged by many factors in accessing the PDCS.
- Outreach – Customers and potential customers are often aware of missed opportunities to inform them of entitlements.
- Attitudes – Although there were claims of hostile treatment of BME customers by PDCS staff there is little evidence to support them (see Section 4.2). There is some evidence of the stereotyping of BME groups as, for example, not wanting to make claims or as wanting to care for their family members without State intervention (see Section 4.2).
- Monitoring – There has been poor ethnic monitoring of take up of benefits and, to a lesser extent, satisfaction with services (see Sections 1.3 and 4.2).

## **5.2 Why less uptake?**

### **5.2.1 Personal factors**

Many of the factors discussed in the above section are relevant here and we need not restate them unless there are additional points to be made. Two further factors warrant attention.

- Negative attitudes to claiming benefit: a number of studies investigated the idea that some BME individuals were unlikely to claim benefit because they disliked taking State handouts or charity. There is a little evidence for this in relation to some older people, for example, in the Chinese community; but overall it is not a strong theme. There is a little more evidence that BME individuals, such as some Asian women, would not seek hands-on help in caring for a relative. This does not imply that they would refuse benefits paid for this care, however; and we found no evidence of such an attitude. Finally, there is some evidence that benefits that are tagged with the terms 'disability' and 'carer' might be avoided or misunderstood by eligible BME individuals (see Section 2.4).
- Fear of investigation: there is a little evidence that individuals might avoid making claims to the PDCS because they are afraid either that they will lose benefits they already have or that it will trigger investigation into their personal affairs by other Government agencies, such as the Home Office (see Section 3.2.2).

### 5.2.2 Local factors

Where there is a role expectation on a family member, usually a woman, to take multiple caring roles that person has double jeopardy in terms of satisfaction and uptake. Their entitlement picture is complex making even more difficult the process of claiming; and the time available in which to go through this process is very constrained. Furthermore, the individuals are often disadvantaged in terms of personal factors as well, such as limited literacy and language skills. We have argued that whilst this is true for all, some BME customers are more likely to suffer this double jeopardy.

Community attitudes to disability might constrain individuals in claiming the relevant benefits. As well as this, there are sometimes negative attitudes to those that claim benefits, other than older person benefits, as being, for example, scroungers. Such a view is not held solely within BME communities, of course; but the significance here is it adds to the atmosphere in which individuals may be afraid to claim (see Section 3.2.2).

There is no evidence that the extended family in BME communities inhibits benefit claims through providing itself all the help the individual needs. There is evidence that some families are critical and judgemental of disabled individuals and carers; and some evidence that individuals might be encouraged to keep a disabled child's presence secret in order to protect the prospects of other family members (see Section 3.2.2).

The majority of evidence concerning local organisations is, on the face of it, positive. Such organisations are usually the first port of call for BME individuals in the process of making a claim; and the PDCS uses non-statutory organisations in outreach work. However, there are issues with local organisations that can negatively affect satisfaction and uptake of the PDCS. We have already mentioned the variable quality of such groups; they are also often underfunded. And reliance

on such groups creates an equity problem for the PDCS as the coverage they provide for individuals is uneven (see Sections 3.4.1 and 3.4.2). One individual might have access to a great deal of non-statutory help in making a claim; another, very little.

### 5.2.3 PDCS system

Most of the points already made in the section concerning PDCS factors affecting satisfaction are also pertinent here.

## 5.3 What interventions help?

The PDCS in its equality scheme outlines measures it is taking that are intended to address many of the problems of access, outreach, attitudes and monitoring (DWP, 2009). For access, it is using a professional telephone interpretation company, 'thebigword'; it is using a mystery shopper auditing system; it is using leaflets in various languages that immediately signpost individuals to the relevant help and information; and it is taking measures to simplify processes. It has targeted communications at vulnerable or 'hard-to-reach' groups, including BME groups. It has undertaken many initiatives in staff training to improve attitudes and interaction with BME customers. It also endeavours to have a staff profile that matches the community it serves. Finally, it is developing its monitoring systems particularly in relation to satisfaction of BME customers.

At present, there is almost no evidence on the success of these measures. For example, it would be useful to know how customers rate the interpretation service given that the PDCS now seems to use it as a mainstay in issues to deal with ESOL customers. Other things being equal, it seems reasonable to expect improvements in BME customer satisfaction. However, there are two structural problems for the PDCS.

The first is that customers of the PDCS will often have an opinion based on their dealings with the whole welfare system rather than the PDCS. A poor experience with a social worker or health visitor might negatively impact the customer's feelings toward the PDCS. The impact of this problem is potentially increased by the reliance of the PDCS on third sector organisations outside of its control. Where these services are uneven in quality and group coverage, some individuals will likely face difficulties in smoothly accessing their entitlements and therefore report a less satisfactory experience with the PDCS.

This connects to the second structural problem: the PDCS is constrained in the measures it takes to attract customers in the first place. It does not, for example, proactively give welfare rights advice in the manner of that performed in Moffatt's (2009) study where outreach workers performed a 'benefits check' for older people to ascertain whether or not they had unclaimed entitlements. Yet much of the dissatisfaction of BME customers relates to the inadequacy of how they were made aware of the possible benefits in the first place (see Sections 4.2 and 4.4). There are structural constraints in the PDCS in its attempting to improve uptake of

benefits by BME customers. These might be overcome to some extent by the use of other professional health and social care organisations. There are many examples in the evidence of individuals who were helped (or not) by, for example, a GP or Health Visitor in finding out that they might be entitled to claim. As well as this, the National Support Team for Health Inequalities views ensuring people receive their benefit entitlements as a health inequality issue. If health professionals are able as part of their public health role proactively to inform people of possible benefits entitlements this could increase uptake and satisfaction for the PDCS. One model is having a benefits advisor sitting in a GP surgery several days a week to provide information.

To summarise, there is insufficient evidence to know whether the interventions planned or undertaken by the PDCS will help; but it seems reasonable to believe that some will. However, there are important areas of dissatisfaction that the PDCS is constrained in addressing.

## 5.4 Gaps in the evidence

There is little direct evidence relating to BME customers of TPS and DCS and what exists is dominated by research on Pakistani and Bangladeshi customers (although there are exceptions, such as Barnard (2003)). This report and the findings summarised in this chapter have to be read with that warning in mind. There are gaps in many areas of the evidence.

In the first place, the predominance of Pakistani and Bangladeshi groups in the evidence means there are gaps; these are increasing with the diversity of the population and new migrant groups. There is a danger of over-generalising from the limited data currently available. Different communities have different resources, networks of information and preferences for modes of communication.

The recent House of Commons report is critical of the evidence on BME uptake of Pension Credit (Britain 2009). This links us to one of the most significant gaps in the evidence; there is no evidence from the PDCS's own research, and little from elsewhere, addressing the uptake by BME individuals of benefits other than Pension Credit. This is, then, an important measure of equity that is unexamined; it is also, we would hypothesise, a useful marker of satisfaction; where there is good uptake of a benefit there is likely to be increased satisfaction of customers. However, the challenge of uncovering the people who have not made claims is formidable given that, by definition, they are unknown to the PDCS.

Whilst the journey for some customers is fairly straightforward, for example, those on state pension, for others the journey is less clear. The ways in which people come to claim DLA are, we suspect, numerous. The indirect evidence suggests that local organisations and word-of-mouth are very important. But more data are needed for this area in which the issues of satisfaction, uptake and equity come together. It would be useful for the PDCS to develop a picture of the different journeys its customers taking; it would help the organisation see where the problems are and how these can be addressed.

## 5.5 Conclusion

Direct evidence examining satisfaction with and uptake of PDCS services by BME customers is scant and much of it is descriptive. Looking for reasons for lower satisfaction and uptake therefore requires taking into account less direct material. This fact alongside methodological issues results in a need for caution in interpretation. However, the findings presented here should be combined with evidence gleaned from internal scrutiny to identify appropriate responses within the context of: current priorities; funding constraints; and actions already implemented (but perhaps not yet established or evaluated) as part of PDCS's Race Equality Plan.





# Appendix A

## Search strategy

DWP database search

### Databases searched

ASSIA, Sociological Abstracts, JSTOR, Social Care Online

### Key terms

**Minority Groups:** ethnic\*, rac\*, cultur\*, minority, religion, language, BME, Asian British, black British, Chinese, Indian, Pakistani, Bangladeshi, black Caribbean, black African

**Older people:** older people, elder\*, age\*

**Disabled:** disabled, chronic illness, incapacity

**Benefits:** disability living allowance, attendance allowance, carers allowance, pension

*Please note that the 'duplicates' referred to in this document are just within the database that was being searched at the time. Duplicates across databases are only picked up once they are imported into Refworks.*

Searches (1997 – 2010)

### Benefits and Minority Groups search terms

ASSIA

1. disability living allowance (title) + ethnic\* (anywhere) – 0 results
2. disability living allowance (abstract) + ethnic\* (anywhere) – 0 results
3. disability living allowance (anywhere) + ethnic\* (anywhere) – 0 results
4. disability living allowance (anywhere) + rac\* (anywhere) – 0 results
5. disability living allowance (anywhere) + cultur\* (anywhere) – 0 results

6. disability living allowance (anywhere) + minority (anywhere) – 0 results
7. disability living allowance (anywhere) + religion (anywhere) – 0 results
8. disability living allowance (anywhere) + language (anywhere) – 0 results
9. disability living allowance (anywhere) + BME (anywhere) – 0 results
10. disability living allowance (anywhere) – 20 results (imported)
  
11. attendance allowance (anywhere) – 7 results (imported – 2 duplications)
12. attendance allowance (anywhere) + ethnic\* (anywhere) – 0 results
13. attendance allowance (anywhere) + rac\* (anywhere) – 0 results
14. attendance allowance (anywhere) + cultur\* (anywhere) – 0 results
15. attendance allowance (anywhere) + minority (anywhere) – 0 results
16. attendance allowance (anywhere) + religion (anywhere) – 0 results
17. attendance allowance (anywhere) + language (anywhere) – 0 results
18. attendance allowance (anywhere) + BME (anywhere) – 0 results
  
19. carers allowance (anywhere) – 0 results
  
20. pension (anywhere) – 408 results (not imported as not all UK based)
21. pension (anywhere) + UK (anywhere) – 157 results (not imported as still not all UK based)
22. pension (anywhere) + UK (abstract) – 18 results (imported)
23. pension (anywhere) + UK (abstract) + ethnic\* (anywhere) – 0 results
24. pension (anywhere) + UK (abstract) + rac\* (anywhere) – 0 results
25. pension (anywhere) + UK (abstract)+ cultur\* (anywhere) – 2 results (duplicated)
26. pension (anywhere) + UK (abstract)+ minority (anywhere) – 0 results
27. pension (anywhere) + UK (abstract)+ religion (anywhere) – 0 results
28. pension (anywhere) + UK (abstract)+ language (anywhere) – 0 results
29. pension (anywhere) + UK (abstract)+ BME (anywhere) – 0 results
  
30. winter fuel (anywhere) – 0 results
31. benefits (anywhere) + older people (anywhere) + UK (abstract) – 14 results (benefits too general a term i.e. as a verb)

32. social security (anywhere) + older people (anywhere) + UK (abstract) – 1 result (imported)
33. social security (anywhere) + elder\* (anywhere) + UK (abstract) – 2 results (imported – 1 duplicated)
34. social security (anywhere) + age\* (anywhere) + UK (abstract) – 5 results (too general a term)
35. social security (anywhere) + geriatric (anywhere) + UK (abstract) – 1 result (duplicated)
  
36. disability living allowance (abstract) + UK (abstract) + Asian British, black British, Chinese (abstract) – 0 results
37. disability living allowance (abstract) + UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean – 0 results
38. attendance allowance (abstract) + UK (abstract) + Asian British, black British, Chinese (abstract) – 0 results
39. attendance allowance (abstract) + UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean – 0 results
40. carers allowance (abstract) + UK (abstract) + Asian British, black British, Chinese (abstract) – 0 results
41. carers allowance (abstract) + UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean – 0 results
42. pension (abstract) + UK (abstract) + Asian British, black British, Chinese (abstract) – 0 results
43. pension (abstract) + UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean – 0 results
44. older, elder\*, age\* (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) (imported) – 202 results (imported)
45. older, elder\*, age\* (abstract) + UK (abstract) + Asian British, black British, Chinese (abstract) – 8 results (duplicated)
46. older, elder\*, age\* (abstract) + UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean (abstract) – 17 results (imported)
47. disabled, chronic illness, incapacity (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) 7 results (5 imported – 2 duplicates)
48. disabled, chronic illness, incapacity + UK (abstract) + Asian British, black British, Chinese (abstract) – 1 result (imported)
49. disabled, chronic illness, incapacity+ UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean (abstract) – 1 result (duplicated)

## Sociological abstracts

1. disability living allowance (anywhere) – 6 results (imported)
2. disability living allowance (anywhere) + ethnic\* (anywhere) – 2 results (duplicated)
3. disability living allowance (anywhere) + rac\* (anywhere) – 1 result (duplicated)
4. disability living allowance (anywhere) + cultur\* (anywhere) – 1 result (duplicated)
5. disability living allowance (anywhere) + minority (anywhere) – 1 result (duplicated)
6. disability living allowance (anywhere) + religion (anywhere) – 0 results
7. disability living allowance (anywhere) + language (anywhere) – 0 results
8. disability living allowance (anywhere) + BME (anywhere) – 0 results
  
9. attendance allowance (anywhere) – 2 results (imported)
10. attendance allowance (anywhere) + ethnic\* (anywhere) – 0 results
11. attendance allowance (anywhere) + rac\* (anywhere) – 0 results
12. attendance allowance (anywhere) + cultur\* (anywhere) – 0 results
13. attendance allowance (anywhere) + minority (anywhere) – 0 results
14. attendance allowance (anywhere) + religion (anywhere) – 0 results
15. attendance allowance (anywhere) + language (anywhere) – 0 results
16. attendance allowance (anywhere) + BME (anywhere) – 0 results
  
17. carers allowance (anywhere) – 0 results
  
18. pension (anywhere) + UK (abstract) – 80 results (imported)
19. pension (anywhere) + UK (abstract) + ethnic\* (anywhere) – 7 results (duplicated)
20. pension (anywhere) + UK (abstract) + rac\* (anywhere) – 10 results (duplicated)
21. pension (anywhere) + UK (abstract) + cultur\* (anywhere) – 20 results (duplicated)
22. pension (anywhere) + UK (abstract) + minority (anywhere) – 7 results (duplicated)
23. pension (anywhere) + UK (abstract) + religion (anywhere) – 2 results (duplicated)
24. pension (anywhere) + UK (abstract) + language (anywhere) – 2 results (duplicated)
25. pension (anywhere) + UK (abstract) + BME (anywhere) – 0 results

- 26.winter fuel (anywhere) – 0 results
- 27.social security (anywhere) + older people (anywhere) + UK (abstract) – 18 result (imported – 1 duplicated)
- 28.social security (anywhere) + elder\* (anywhere) + UK (abstract) – 17 results (imported – 5 duplicated)
- 29.social security (anywhere) + geriatric (anywhere) + UK (abstract) – 1 result (duplicated)
- 30.older, elder\*, age\* (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) (imported) – 120 results (imported)
- 31.older, elder\*, age\* (abstract) + UK (abstract) + Asian British, black British, Chinese (abstract) – 6 results (1 duplicated)
- 32.older, elder\*, age\* (abstract) + UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean (abstract) – 11 results (1 duplicated – 10 imported)
- 33.disabled, chronic illness, incapacity (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) 6 results
- 34.disabled, chronic illness, incapacity+ UK (abstract) + Asian British, black British, Chinese (abstract) – 0 results
- 35.disabled, chronic illness, incapacity+ UK (abstract) + Indian, Pakistani, Bangladeshi, black Caribbean (abstract) – 0 results

#### JSTOR

1. disability living allowance (anywhere) – 293 results (not imported as not all UK based)
2. disability living allowance (anywhere) + UK (abstract) – 9 results (imported)
3. disability living allowance (anywhere) + ethnic\* (anywhere) – 1 result (duplicated)
4. disability living allowance (anywhere) + UK (abstract) + rac\* (anywhere) – 0 results
5. disability living allowance (anywhere) + UK (abstract) + cultur\* (anywhere) – 1 result (duplicated)
6. disability living allowance (anywhere) + UK (abstract) + minority (anywhere) – 2 results (duplicated)
7. disability living allowance (anywhere) + UK (abstract) + religion (anywhere) – 1 result (duplicated)
8. disability living allowance (anywhere) + UK (abstract) + language (anywhere) – 2 results (duplicated)

9. disability living allowance (anywhere) + UK (abstract) + BME (anywhere) – 0 results
- 10.attendance allowance (anywhere) – 502 results (not imported as not all UK based)
- 11.attendance allowance (anywhere) + UK (abstract) – 9 results (5 duplicates)
- 12.attendance allowance (anywhere) + ethnic\* (anywhere) – 1 result (duplicated)
- 13.attendance allowance (anywhere) + rac\* (anywhere) – 0 results
- 36.attendance allowance (anywhere) + cultur\* (anywhere) – 2 results (duplicated)
- 14.attendance allowance (anywhere) + minority (anywhere) – 1 result (duplicated)
- 15.attendance allowance (anywhere) + religion (anywhere) – 1 result (duplicated)
- 16.attendance allowance (anywhere) + language (anywhere) – 3 results (duplicated)
- 17.attendance allowance (anywhere) + BME (anywhere) – 0 results
- 18.carers allowance (anywhere) – 9 results (not imported as not all UK based)
- 19.carers allowance (anywhere) = UK (abstract) – 5 results (imported – 2 duplications)
- 20.pension (anywhere) + UK (abstract) – 50 results (imported – 29 duplications)
- 21.winter fuel (anywhere) – 2,582 results (not a suitable term for JSTOR)
- 22.social security (anywhere) + elder\* (anywhere) + UK (abstract) – 4 results (comparative studies)
- 23.social security (anywhere) + geriatric (anywhere) + UK (abstract) – 0 results
- 24.older (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) (imported) – 211 results (too broad a term for JSTOR)
- 25.age\* (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) (imported) – 212 results (too broad a term for JSTOR)
- 26.elderly (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) (imported) – 211 results (too broad a term for JSTOR)
- 27.disabled, (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) 211 results (too broad for JSTOR)

28.chronic illness (abstract) + UK (abstract) ethnic\*, rac\*, cultur\* (abstract) 211 results (too broad for JSTOR)

29.incapacity + UK (abstract) + Asian British, black British, Chinese (abstract) – 211 results

Social Care Online

1. attendance allowance (anywhere) – 12 results (imported)
2. disability living allowance (anywhere) – 46 results (imported – 15 duplicates)
3. State retirement pensions (anywhere) – 4 results (imported)





# Appendix B

## Organisations contacted and reports retrieved

[1] Black and Minority Ethnic (BME) and claimant-group focused

### Funding bodies

| Name of organisation   | Documents accessed/information received via request |
|--|---|
| Equality and Human Rights Commission (EHRC) (and predecessors) | Yes   |
| Joseph Rowntree Foundation                                     | Yes   |
| Nuffield Foundation  |   |

### Carers

| Name of organisation                                  | Documents accessed/information received via request |
|---|---|
| BME Carers  | Yes   |
| National Black Carer and Carer Workers Network        | Yes   |
| Mecopp:   | Yes   |
| Carers Information Service                            | Yes   |
| Lancashire Asian Carers Forum                         |   |
| Caring for Carers Association: Hammersmith and Fulham |   |
| Carers Bucks:   | Yes   |

**Disabled (long-term sick)**

| <b>Name of organisation</b>                        | <b>Documents accessed/information received via request</b> |
|--|--|
| Afiya Trust  | Yes  |
| Race Equality Foundation                           |  |
| Black Mental Health                                |  |
| National BME Mental Health Network                 |  |
| National Learning Disability and Ethnicity Network |  |
| Asian Disability Network in Bradford               |  |

**Older people**

| <b>Name of organisation</b>                       | <b>Documents accessed/information received via request</b> |
|---|--|
| Policy Research Institute on Ageing and Ethnicity |  |

[2] Non-BME but claimant-group focused:

**Carers**

| <b>Name of organisation</b>      | <b>Documents accessed/information received via request</b> |
|----------------------------------|--|
| Carers                           | Yes  |
| Barnados (Young carers)          |  |
| HASCAS:                          |  |
| Carers UK                        | Yes  |
| Princess Royal Trust for Carers: |  |

**Disabled (long-term sick)**

| <b>Name of organisation</b>                | <b>Documents accessed/information received via request</b> |
|--|--|
| RNIB                                       | Yes  |
| Social Information on Disability           | Yes  |
| Rethink – mental health                    | Yes  |
| Mencap                                     | Yes  |
| British Institute of Learning Disabilities |  |
| ARC  |  |
| Sign Translate:                            |  |
| Deaf Council                               |  |
| HEROS                                      |  |
| Diabetes UK                                |  |

**Older people**

| <b>Name of organisation</b>          | <b>Documents accessed/information received via request</b> |
|--------------------------------------|--|
| Age Concern                          | Yes  |
| Help the Aged                        | Yes  |
| Age UK                               |  |
| Leeds Older People Forum             | Yes  |
| Fuel poverty (CSE)                   |  |
| Affordable Warmth strategy Edinburgh |  |
| Equality Scotland                    |  |

**[3] BME but not claimant-group focused**

| <b>Name of organisation</b> | <b>Documents accessed/information received via request</b> |
|-----------------------------|--|
| Institute of Race Relations | Yes  |
| Black Information Link      |  |
| Equality Challenge Unit     | Yes  |



# Appendix C

## Recommendations from 'Out of Sight'

SUMMARY OF RECOMMENDATIONS

Devise strategies to ensure men and women learn about benefit entitlements: for ethnic minority communities where women are particularly isolated, use double-pronged marketing programmes to reach them – directly by targeting women's social networks indirectly via campaigns directed to men

Ensure that claims trigger related entitlement information: once people are 'in the system', ensure all benefits applications automatically trigger information about related entitlements for which claimants or their relatives may qualify.

Provide diverse outreach services to local communities: take the initiative. Deliver information and advice directly to places used by disabled people and carers – don't rely on claimants making the first move. Work with ethnic minority arts groups to find promotion formats accessible to their communities.

Provide regular outreach clinics: use community locations so claimants can complete benefits applications in familiar local surroundings. Ensure locations chosen are used by ethnic minority women.

Provide realistic statutory support to voluntary advice organisations: provide publicly funded support to advice-giving voluntary organisations. In particular, help them meet staffing and training needs.

Establish an ethnic minority voluntary sector support strategy: conduct regular consultation with community groups, especially disability and women's organisations. Build advice partnerships with ethnic minority groups. Fund advice skills training. Support capacity building initiatives. Provide up-to-date information resources. Help with premises and IT needs.

Develop mainstream voluntary sector support to ethnic minority communities: help ethnic minority community groups by providing assistance such as outreach advice services in community premises, access to free or low cost training, information materials at reduced rates etc.

Extend statutory support to outreach initiatives: build outreach partnerships and consortia with the voluntary sector, the health service and social services departments, so voluntary organisations can set up advice clinics in community locations like health centres etc.

Advertise and promote help line availability: market the existing DWP telephone information and form filling service (Benefits Enquiry Line) and the interpreter supported Language Lines.

| TARGET AUDIENCES   | Department for Work and Pensions | Direct government departments and services | Voluntary/charitable organisations |
|--|----------------------------------|--|------------------------------------|
| Devise strategies to ensure men and women learn about benefit entitlements: for ethnic minority communities where women are particularly isolated, use double-pronged marketing programmes to reach them – directly by targeting women's social networks indirectly via campaigns directed to men  | •                                | •  | •                                  |
| Ensure that claims trigger related entitlement information: once people are 'in the system', ensure all benefits applications automatically trigger information about related entitlements for which claimants or their relatives may qualify.   | •                                | •  | •                                  |
| Provide diverse outreach services to local communities: take the initiative. Deliver information and advice directly to places used by disabled people and carers – don't rely on claimants making the first move. Work with ethnic minority arts groups to find promotion formats accessible to their communities.  | •                                | •  | •                                  |
| Provide regular outreach clinics: use community locations so claimants can complete benefits applications in familiar local surroundings. Ensure locations chosen are used by ethnic minority women.   | •                                | •  | •                                  |
| Provide realistic statutory support to voluntary advice organisations: provide publicly funded support to advice-giving voluntary organisations. In particular, help them meet staffing and training needs.  | •                                | •  | •                                  |
| Establish an ethnic minority voluntary sector support strategy: conduct regular consultation with community groups, especially disability and women's organisations. Build advice partnerships with ethnic minority groups. Fund advice skills training. Support capacity building initiatives. Provide up-to-date information resources. Help with premises and IT needs. | •                                | •  | •                                  |
| Develop mainstream voluntary sector support to ethnic minority communities: help ethnic minority community groups by providing assistance such as outreach advice services in community premises, access to free or low cost training, information materials at reduced rates etc.   | •                                | •  | •                                  |
| Extend statutory support to outreach initiatives: build outreach partnerships and consortia with the voluntary sector, the health service and social services departments, so voluntary organisations can set up advice clinics in community locations like health centres etc.  | •                                | •  | •                                  |
| Advertise and promote help line availability: market the existing DWP telephone information and form filling service (Benefits Enquiry Line) and the interpreter supported Language Lines.   | •                                | •  | •                                  |

SUMMARY OF RECOMMENDATIONS

Increase home visiting provision: promote the DWP home visiting service to assist isolated ethnic minority women claimants. More home visiting by voluntary advice groups and other statutory services would also help isolated claimants' benefits access

Use new technology to improve access to benefits: enable claimants to get benefits information and process their claims close to home, by using modern interactive communication technology located in mainstream and ethnic minority community locations. Use new technology to overcome local staffing limitations e.g. providing 'face-to-face' own-language advice to ethnic minority claimants via video link.

**Accountability**

Ensure effective local accountability: designate local DWP lead officers to oversee complaints, conduct local consultation and develop marketing strategies targeted to harder-to-reach ethnic minority disabled women and carers.

Maintain well publicised accessible complaints and praise procedures: ensure complaints procedures are well publicised and user-friendly, and accompanied by equally prominent ways of recording praise for good service.

**Ethnic monitoring & research**

Implement an ethnic monitoring programme: aim to issue the first ethnic monitoring data no later than mid 2006.

Establish a disability/carer specific research programme: identify priority areas examining the interaction between ethnicity, gender and the disability and carers benefits system.

**Training**

Ensure staff training relates to the real world: ensure race equality training is supported, not undermined, by other policies. Work with community organisations to achieve ethnically sensitive and relevant training.

**System review**

Consider establishing a single benefits entry point: examine the practicalities of introducing procedures that enable claimants to trigger assessments for all potential benefits via a single claim document.

Consider simplifying the benefits system: consider amalgamating and rationalising the range of benefits available.

| TARGET AUDIENCES  | Department for Work and Pensions | Direct government departments and services | Voluntary/charitable organisations |
|---|----------------------------------|--|------------------------------------|
| Increase home visiting provision: promote the DWP home visiting service to assist isolated ethnic minority women claimants. More home visiting by voluntary advice groups and other statutory services would also help isolated claimants' benefits access  | •                                | •  | •                                  |
| Use new technology to improve access to benefits: enable claimants to get benefits information and process their claims close to home, by using modern interactive communication technology located in mainstream and ethnic minority community locations. Use new technology to overcome local staffing limitations e.g. providing 'face-to-face' own-language advice to ethnic minority claimants via video link. | •                                | •  | •                                  |
| <b>Accountability</b>   |                                  |  |                                    |
| Ensure effective local accountability: designate local DWP lead officers to oversee complaints, conduct local consultation and develop marketing strategies targeted to harder-to-reach ethnic minority disabled women and carers.  | •                                | •  | •                                  |
| Maintain well publicised accessible complaints and praise procedures: ensure complaints procedures are well publicised and user-friendly, and accompanied by equally prominent ways of recording praise for good service.   | •                                | •  | •                                  |
| <b>Ethnic monitoring &amp; research</b>   |                                  |  |                                    |
| Implement an ethnic monitoring programme: aim to issue the first ethnic monitoring data no later than mid 2006.   | •                                | •  | •                                  |
| Establish a disability/carer specific research programme: identify priority areas examining the interaction between ethnicity, gender and the disability and carers benefits system.  | •                                | •  | •                                  |
| <b>Training</b>   |                                  |  |                                    |
| Ensure staff training relates to the real world: ensure race equality training is supported, not undermined, by other policies. Work with community organisations to achieve ethnically sensitive and relevant training.  | •                                | •  | •                                  |
| <b>System review</b>  |                                  |  |                                    |
| Consider establishing a single benefits entry point: examine the practicalities of introducing procedures that enable claimants to trigger assessments for all potential benefits via a single claim document.  | •                                | •  | •                                  |
| Consider simplifying the benefits system: consider amalgamating and rationalising the range of benefits available.  | •                                | •  | •                                  |

SUMMARY OF RECOMMENDATIONS

Summary of recommendations

Out of Sight makes 39 recommendations for changes in benefits policy, practice and administration. Many would substantially improve interaction between claimants generally and the benefits system, but are included here because they would all contribute to promoting equality of opportunity for ethnic minorities who are disabled or have caring responsibilities, and are seeking to obtain their statutory benefits entitlements.

Key principles

- 1 Be user-centred: review all information materials and delivery methods to find which work for disabled and carer benefits claimants and which don't.
- 2 Be flexible: be flexible and creative. One size won't fit all, especially in a multicultural and gender-divided society. Try a range of methods and build an information delivery portfolio for getting benefits information across.
- 3 Promote best practice: learn from experience. Don't waste time reinventing the wheel. Search out best practice and make sure it is universally disseminated.

Specific recommendations

Access to information and services

Give positive messages: always emphasise a positive message. Disabled and carer claimants are not looking for charity, they are pursuing their legal rights.

Keep forms short, relevant and easy to read: keep benefits application forms easy to understand. Ensure all questions asked are essential – and that claimants understand their purpose and relevance. Check with users which colours, typefaces, layouts and formats they find easiest to handle.

Review business language constantly: consumer test information leaflets and forms regularly, and on every kind of audience, including harder-to-reach women and ethnic minorities, to minimise comprehension difficulties and flag up problems.

Be courteous, friendly, helpful and accessible to non-English speakers: review all letters to ensure they are courteous, comprehensive and helpful, giving reasons for decisions and follow up guidance. Ensure weak English speakers always get written translations of letters or interpreter services.

Ensure a welcome for everyone at Jobcentre Plus offices: check with disabled people and their specialist organisations, to ensure any premises people have to visit in connection with their benefits claims are fully disabled-accessible. Publicise the availability of private interview rooms, and the option of same sex interviewers and medical examiners, especially to female minority claimants.

| TARGET AUDIENCES   | Department for Work and Pensions | Direct government departments and services | Voluntary/charitable organisations |
|--|----------------------------------|--|------------------------------------|
| Devise strategies to ensure men and women learn about benefit entitlements: for ethnic minority communities where women are particularly isolated, use double-pronged marketing programmes to reach them – directly by targeting women's social networks indirectly via campaigns directed to men  | •                                | •  | •                                  |
| Ensure that claims trigger related entitlement information: once people are 'in the system', ensure all benefits applications automatically trigger information about related entitlements for which claimants or their relatives may qualify.   | •                                | •  | •                                  |
| Provide diverse outreach services to local communities: take the initiative. Deliver information and advice directly to places used by disabled people and carers – don't rely on claimants making the first move. Work with ethnic minority arts groups to find promotion formats accessible to their communities.  | •                                | •  | •                                  |
| Provide regular outreach clinics: use community locations so claimants can complete benefits applications in familiar local surroundings. Ensure locations chosen are used by ethnic minority women.   | •                                | •  | •                                  |
| Provide realistic statutory support to voluntary advice organisations: provide publicly funded support to advice-giving voluntary organisations. In particular, help them meet staffing and training needs.  | •                                | •  | •                                  |
| Establish an ethnic minority voluntary sector support strategy: conduct regular consultation with community groups, especially disability and women's organisations. Build advice partnerships with ethnic minority groups. Fund advice skills training. Support capacity building initiatives. Provide up-to-date information resources. Help with premises and IT needs. | •                                | •  | •                                  |
| Develop mainstream voluntary sector support to ethnic minority communities: help ethnic minority community groups by providing assistance such as outreach advice services in community premises, access to free or low cost training, information materials at reduced rates etc.   | •                                | •  | •                                  |
| Extend statutory support to outreach initiatives: build outreach partnerships and consortia with the voluntary sector, the health service and social services departments, so voluntary organisations can set up advice clinics in community locations like health centres etc.  | •                                | •  | •                                  |
| Advertise and promote help line availability: market the existing DWP telephone information and form filling service (Benefits Enquiry Line) and the interpreter supported Language Lines.   | •                                | •  | •                                  |

SUMMARY OF RECOMMENDATIONS

Provide ethnic minority claimants with own community support: review and revise employment policies and practices to ensure employment of ethnic minority staff at all levels from frontline to senior management. Where there are no appropriate ethnic minority staff, use new technology to deliver 'face-to-face' services

Establish reliable appointment systems: give claimants timed appointments and stick to them.

Effective marketing: develop eye catching flyers and posters signposting sources of practical help and advice. To encourage benefits take-up, run regular high profile media promotions, like the Inland Revenue's tax credits and tax returns campaigns. Make full use of ethnic minority media (press and radio) to promote benefits entitlements.

Recognise the limitations or written translated materials: though translations are helpful, do not overestimate their importance. Literacy levels in mother tongue languages are low, while some languages have no written form e.g. Sylheti.

Ensure written translated leaflets are on display and up to date: provide high quality translated signposting and information materials – and ensure they are always prominently displayed and stocks replenished.

Audio-visual formats: work jointly with the voluntary sector to develop story-based video and audio-tape information materials, to get round isolation and language and literacy problems among ethnic minority claimants and provide resources suitable for community-based learning.

Ensure professional interpreting provision: ensure benefits claimants with poor English language skills have prompt access at every stage to trained and professional own-language facilities who have appropriate benefits expertise and interpreter/translator training. Never use 'amateurs' to bridge the language gap.

Include disability and carer issues in education, professional training etc: include disability and carer issues in the mainstream of our lives via school education, in core professional training for social care, education and health personnel, and as part of media information campaigns.

Use direct mail: send benefits take-up information to all homes on an annual basis, via a dedicated benefits promotion delivery, or by piggy backing onto other direct mail distribution such as council tax demands. Where appropriate, include translated versions.

| TARGET AUDIENCES   | Department for Work and Pensions | Direct government departments and services | Voluntary/charitable organisations |
|--|----------------------------------|--|------------------------------------|
| Devise strategies to ensure men and women learn about benefit entitlements: for ethnic minority communities where women are particularly isolated, use double-pronged marketing programmes to reach them – directly by targeting women's social networks indirectly via campaigns directed to men  | •                                | •  | •                                  |
| Ensure that claims trigger related entitlement information: once people are 'in the system', ensure all benefits applications automatically trigger information about related entitlements for which claimants or their relatives may qualify.   | •                                | •  | •                                  |
| Provide diverse outreach services to local communities: take the initiative. Deliver information and advice directly to places used by disabled people and carers – don't rely on claimants making the first move. Work with ethnic minority arts groups to find promotion formats accessible to their communities.  | •                                | •  | •                                  |
| Provide regular outreach clinics: use community locations so claimants can complete benefits applications in familiar local surroundings. Ensure locations chosen are used by ethnic minority women.   | •                                | •  | •                                  |
| Provide realistic statutory support to voluntary advice organisations: provide publicly funded support to advice-giving voluntary organisations. In particular, help them meet staffing and training needs.  | •                                | •  | •                                  |
| Establish an ethnic minority voluntary sector support strategy: conduct regular consultation with community groups, especially disability and women's organisations. Build advice partnerships with ethnic minority groups. Fund advice skills training. Support capacity building initiatives. Provide up-to-date information resources. Help with premises and IT needs. | •                                | •  | •                                  |
| Develop mainstream voluntary sector support to ethnic minority communities: help ethnic minority community groups by providing assistance such as outreach advice services in community premises, access to free or low cost training, information materials at reduced rates etc.   | •                                | •  | •                                  |
| Extend statutory support to outreach initiatives: build outreach partnerships and consortia with the voluntary sector, the health service and social services departments, so voluntary organisations can set up advice clinics in community locations like health centres etc.  | •                                | •  | •                                  |
| Advertise and promote help line availability: market the existing DWP telephone information and form filling service (Benefits Enquiry Line) and the interpreter supported Language Lines.   | •                                | •  | •                                  |

# Appendix D: Recommendations from ‘Delivery of Services...’

## **Recommendations from House of Commons Work and Pensions Committee Report: *Delivery of services to ethnic minority clients: Fourth report of session 2004-5***

1. The Committee notes the Race Equality Scheme Progress Report and recommends that by 31 December 2005 the Department develops further targets to improve race equality beyond 2005. (Paragraph 29)
2. In line with the statutory requirement to review the relevant functions, policies and proposed policies contained in the Race Equality Scheme, the Committee recommends that the Department publishes on time, the statutory three year review of the Scheme to assess what progress has been made on race equality across DWP since May 2002. (Paragraph 33)
3. The Committee recommends that by 31 December 2005 the Department sets long-term and challenging targets for the improved representation of ethnic minority staff, particularly at senior levels, beyond 2005. The Department must improve its own knowledge of its workforce by more effective ethnic monitoring. We believe PCS could do more to assist with this process. (Paragraph 43)
4. The Committee recommends that the Department undertakes by 1 May 2006 a full review of staff procedures to assess their impact on race equality, taking account of factors such as access to training and reasons given for resignation and that it develops an action plan to address any adverse effects of its procedures upon ethnic minority staff. We also recommend that the Department provides substantial further support for existing ethnic minority staff in career progression and takes immediate action to recruit ethnic minority staff at senior levels. (Paragraph 49)



5. The Committee is concerned that proposed job cuts and relocations will have a disproportionate impact on Black and Minority Ethnic (BME) employees, which could contribute to a worsening of relative unemployment levels. The Committee recommends that by 1 May 2006 the Department publishes the race impact assessment of the job cuts and relocations out of London and the South East; the criteria used for selecting staff who are likely to lose their posts; and also the ethnic breakdown of the staff who will be leaving the Department as a result of the job cuts. We also recommend that the Department gives serious consideration to how it will meet the staff ethnicity targets when deciding which staff will be selected for redundancy. (Paragraph 57)

6. The Committee recommends that the Department takes urgent action to implement ethnic monitoring across the Department and its Agencies at both entry point and exit point and for all benefits and services. We also recommend that the Department works closely with the DWP Ethnic Minority Working Party, the Commission for Racial Equality and other representative bodies to ensure that full and proper use is made of the information gathered through ethnic monitoring. (Paragraph 65)

7. The Committee recommends that the habitual residence test and the Social Fund discretionary decisions are subject to ethnic monitoring to establish whether there is a differential impact upon ethnic minorities, and whether those tests are applied differently. (Paragraph 74) 62

8. The Committee recommends that the Department reviews the identification requirements needed to pursue a benefit claim and ensures that staff are fully trained in the identification requirements including the process of referral to the Validity of Marriage Unit. (Paragraph 78)

9. The Committee recommends that the Department examines the option of suspending rather than cancelling payment of benefits while clients are abroad for a time-limited period. We also reiterate our recommendation that, by 1 April 2006, payment of Pension Credit during a temporary absence abroad is brought into line with Housing Benefit and Council Tax Benefit and is paid for up to 13 weeks. (Paragraph 81)

10. The Committee recommends that:

a) the Department undertakes a full assessment of race equality and cultural awareness training, in consultation with external experts, such as the Commission for Racial Equality;

b) the Department ensures that staff receive up-to-date equality training, with annual 'refresher' courses for all staff;

c) training via printed and electronic media is only used to supplement attendance at a training event;

d) all training is tested and evaluated to ensure that it meets the needs of staff and clients. (Paragraph 93)

11. The Committee recommends that the Impact Assessment Tool is urgently applied across the Department to all areas of service delivery as well as to existing and new policies and that the results of the impact assessment are published and acted upon promptly to reduce inequalities for clients and staff and to meet the race relations legislation. (Paragraph 97)

12. The Committee recommends that a breakdown of take-up of means-tested benefits by pensioner households should be provided by ethnic group. (Paragraph 103)

13. The Committee further recommends that research on the estimates of eligibility for Attendance Allowance and Disability Living Allowance should look specifically at eligibility among ethnic minorities. (Paragraph 107)

14. The Committee recommends that the Pension Service collects data from late 2006 on the ethnicity of its customers. (Paragraph 110)

15. As part of its duties under race relations legislation, the Pension Service should evaluate awareness among ethnic minority pensioners about how to access the Pension Service at local level, determine whether the arrangements in place are sufficient to meet their needs and by 1 October 2006 report on the results. (Paragraph 119)

16. The Committee considers local partnership schemes to be essential to the success of the Pension Service and we recommend that areas with higher-than-average ethnic minority populations get additional resources and support for partnership development. (Paragraph 139)

17. The Committee recommends that a larger range of translated material should be made more widely available and that translated material should be updated frequently and put on public display. (Paragraph 154)

18. The Committee recommends that the Department soon carries out an urgent and fundamental re-consideration of:

- a) its plan to address the language needs of clients;
- b) the services it offers to assist clients needing language support; and
- c) its plan to improve awareness amongst senior management. (Paragraph 158)

19. The Committee recommends that the Department develops a language marker on the appropriate IT systems to identify clients needing ongoing language support. We also recommend that clients are given the option of requesting that they receive correspondence in the language of their choice. (Paragraph 162)

20. The Committee recommends that the Department further reforms the current staff language allowance and differentiates between staff who frequently use their linguistic skills and those who are 'casual' users; and that staff who spend more than 25 per cent of their time using a second language should receive a substantial annual allowance, and that those who use their language skills less frequently should be entitled to an annual allowance of at least £520. (Paragraph 165)

21. The Committee is concerned that the staffing cuts and relocations outside London will have a detrimental effect upon the service ethnic minority clients can expect to receive from DWP and that this will be particularly problematic for those with language needs. We recommend that the Department conducts an audit by 31 December 2005 of the languages spoken by staff in London together with an impact assessment of the staff efficiencies; and that by 1 October 2006 a strategy is developed to ensure that clients in London who require language support are not disproportionately and adversely affected by the staffing efficiency measures. (Paragraph 171)

22. The Committee recommends that by 1 May 2006 the Department develops a coherent ethnic minority outreach strategy and works in close partnership with local and community groups in order to meet the information needs of ethnic minorities. The Committee also recommends that a thorough review is undertaken of capacity within advice services serving communities with high minority populations, and other indicators of social need. (Paragraph 174)

23. The Committee recommends that significant additional resources are allocated to promote increased participation in the labour market in the 272 most disadvantaged wards in the UK. (Paragraph 192)

24. The Committee recommends a targeted spend-to-save increase in resources to assist qualified refugees to find suitable work. The Committee also recommends increased support for specialist voluntary sector and not-for-profit organisations providing tailored training courses for refugees to assist them to be able to compete in local labour markets. (Paragraph 210)

# Appendix E

## PDCS race equality scheme action plan

<http://www.dwp.gov.uk/docs/espr-pdcs-2009.pdf>



# Appendix F

## Methodological issues

### **A 6.1 Researching ethnic inequalities**

The UK government has renewed its commitment to tackling ethnic inequalities in the provision, uptake and experience of public services across diverse welfare arenas (Department for Communities and Local Government, 2009). There is increasing demand for better understanding of both the patterns and causes of such inequalities and a growing body of social research that includes a focus on Black and Minority Ethnic (BME) populations. However, as the volume of research addressing ethnic inequalities increases so too do concerns about the scientific and ethical rigour of such work and its potential to translate into positive change (Gunaratnam, 2007; Harriss, 2009; Salway, 2009; Gunaratnam, 2007). Particular issues that require careful consideration include the following:

### **A 6.2 What do we mean by 'ethnicity'?**

The term 'ethnicity' is employed in diverse and contradictory ways. In its most generic form, 'ethnicity' represents a form of social or group identity, drawing on notions of shared origins or ancestry. However, different conceptualisations emphasise different aspects of such group identity (e.g. shared values and norms versus common experiences of racism) and view the processes of ethnic identification differently (e.g. internal processes of identification and belonging versus external labelling and exclusion). Ethnic identities – both in terms of how people are identified and what such identification implies – are not fixed over space and time. We recognise the importance of acknowledging the varied ways in which experiences and welfare outcomes may be shaped by ethnicity and wherever possible have sought to draw on studies that are explicit about the dimensions of ethnicity being explored.

### **A 6.3 How useful and meaningful are ethnic group labels/categories?**

In the main, this report uses UK 2001 Census categories and sub-categories for the BME population. These are: white (Irish, other white); mixed; Asian or Asian British (Indian, Pakistani, Bangladeshi, other Asian); black or black British (black Caribbean, black African, other black); Chinese; other. This is consistent with a majority of government publications and enables comparability across data sources. These statutory categories have also undergone substantial testing to ensure acceptability and meaning to respondents (ONS, 2003 a and b). However, such categories must not be presented as taken-for-granted, natural or neutral. Using fixed categorical ethnic labels is always problematic because ethnicity is fluid and context-specific. The same person may give her ethnicity as Asian, Pakistani, British Muslim or Mirpuri. Similarly, people who might be categorised as the same ethnicity by outsiders might view themselves as different from one another.

Thus ethnic categories are a crude short-hand attempt to capture socially-mediated identities that are inherently complex and variable. Ethnic categories when operationalised in studies do not always delineate groups of people who have common experiences/circumstances. As such, they may often not be adequate proxies for the factors of interest in any particular investigation. Data presented for highly aggregated categories, such as 'Asian', 'black' or 'non-white' are particularly problematic; but even the more refined categories such as Indian or black Caribbean frequently conceal great heterogeneity of circumstances and experiences. Researchers and research users must be alert to the internal diversity of ethnic 'groups' and avoid the tendency to over-generalise or stereotype.

### **A 6.4 How can we explain differences between ethnic groups?**

While comparative analyses between ethnic groups may be useful in flagging up inequalities, researchers must avoid interpreting ethnic associations as explanations. Analyses should seek to identify underlying causal factors rather than simply inferring their existence. There may often be a tendency to assume that differences between minority groups and the white British majority have their origin in cultural practices and beliefs, and indeed it is not uncommon to find people using the term 'ethnicity' to mean 'culture'. Furthermore, even where a wide range of data is available (such as language, knowledge levels, experiences of racism and so on), relevant variables are likely to remain beyond the scope of any analysis, such as historical factors or wider social structures. If research is to produce credible explanations for ethnic inequalities, there are also important considerations relating to sampling, generating comparable data across ethnic groups and analytical approaches that deserve attention (Salway, 2009).

In the present review this requires that particular ethnic correlation with low satisfaction is taken only as the starting point for investigation. Our concern should be to find a third factor between ethnicity and satisfaction that plausibly contributes to low satisfaction and which is present to a higher degree in the

less-satisfied ethnic group. Plausibility is a term of art rather than science but the term can be illustrated in the phenomenon of poor English. This is something that is present to a high degree amongst Pension, Disability and Carers Service (PDCS) customers in the broad 'Asian' category. This seems like something that could be relevant but does not of itself explain the dissatisfaction. However, if we dig deeper into the experiences of those with poor English we might start to find factors that are likely to contribute to poor experiences, such as the use of inadequate translation services or negative interactions with service providers.

### **A 6.5 To what extent has research addressed the issues of greatest concern to BME people?**

Since people from BME groups do not have a strong voice within the social research arena, they have little input into the problems and research questions that are commonly dreamt up by academics or policy makers. This situation may mean that the issues of most concern to minoritised groups are overlooked. A lack of involvement of minorities within the research process can also mean a danger of insensitive representation of these groups in research findings. The evidence we reviewed reflected no deliberate insensitivity. But there may be a tendency to view BME customers solely as the source of problems to resolve rather than focusing on possible strengths that could help resolve the problems between BME communities and the PDCS. Having said that, our inclusion of grey literature from third sector and stakeholder groups should go some way to ensuring that the evidence review presented here reflects the interests, concerns and strengths of the communities it focuses on.

### **A 6.6 Methodological issues: Satisfaction**

The evidence of lack of satisfaction amongst BME customers was the starting point of the study. Satisfaction surveys have been criticised but are currently regarded as an important tool with which to gauge the quality of statutory services. For our purposes, though, an important limitation is they tell us nothing about eligible non-claimants. It is worth noting that much of the material reviewed was driven by the concern not only that BME people experience services as unsatisfactory but also as stressful and exclusionary; something that has a negative impact on quality of life.

In terms of the methods used in the most recent surveys (Howat, 2008; Byrom, 2009), the Disability and Carers Service (DCS) survey is weakened by the use of self-return postal questionnaires and the low response rate. Also, the questionnaires were in English with the offer of a translated questionnaire given on the last page. It is possible only to speculate on what effect the resultant sample might have on the accuracy of the estimates of dissatisfaction derived from the DCS survey; it could be to inflate overall levels of complaint but reduce the level from non-English speakers. As such, the rate of BME dissatisfaction would be underestimated. The sampling in The Pension Service (TPS) survey is not subject to any such clear risk of bias. However, there might be other issues, such as the ethnic identity of the



interviewers, whether BME individuals would be less likely to complain in a face-to-face interview than in an anonymous questionnaire and so on.

Both surveys have fairly small numbers from some ethnic groups. As a result, there is little disaggregation of figures. The DCS report generally uses two categories, white and ethnic minority; the TPS uses white/non-white. The reports have a little further information but there is not much analysis of differences between ethnic groups. There is also no breakdown of responses by important within-group variation, such as socio-economic status or English language capability. The latter is an important limitation; for example, it would be helpful to know the difference in satisfaction levels of those with and without good English as it would enable us to get some idea of the language effect on satisfaction. However, it is unlikely that the sample sizes would sustain such analyses at this stage.

### **A 6.7 Methodological issues: Quantity and quality of the available evidence**

Few studies look explicitly at the initiatives undertaken by either the TPS or DCS in relation to ethnic inequality. There is little that directly examines the experiences of BME customers of TPS or DCS. Most studies that are relevant explore people's experiences and attitudes towards 'the benefit system' more broadly. Even where these focus on disability-related or old-age-related benefits, they tend to gather information that relates to people's overall experiences rather than their specific views or perceptions of TPS or DCS. This approach reflects the fact that the majority of studies have been community-based rather than service-based. But it also reflects the reality of many BME (and majority white) people's experiences of accessing these benefits whereby sources of information, advice and support are commonly individuals and organisations who act as intermediaries and who frequently have no, or tenuous, formal connection to PDCS.

Thus, some elements of respondents' narratives may be easily related to part of PDCS services, such as the common perception that claim forms are too long and complicated. However, other factors, for instance respondent reports of helpful face-to-face assistance from voluntary sector outreach workers who speak their language, relate to the broader 'benefits system' within which the direct actions of PDCS form only a small part. Furthermore, respondents in research studies may not clearly identify the source of support or frustration to which they refer – the origin of workers, helplines, leaflets, offices visited and so on may not clearly be identified. Therefore, unless study designs include an explicit focus on evaluating a particular service, and few do, the information often cannot be related directly to specific policies and/or practices. The result is that much of the information available describes in rather general terms the experiences of BME people who may be eligible for, and may have attempted to access, PDCS-administered benefits. But there are some consistent and persistent themes. The extent to which such studies might inform PDCS policy and practice relates fundamentally to how TPS/DCS view their remit – how far their responsibility reaches and what range of activity/intervention is considered to fall within their scope.

There were further features in the evidence that we needed to bear in mind in our review. In the first place, there is a bias in the evidence base towards Asian communities, and particularly towards Pakistanis. Some groups had little representation in the evidence; for example, Chinese and black Africans. This partly reflects the make up of the BME population. But it means we should be cautious in generalising any findings across all BME groups since circumstances and experiences vary widely.

There is also a bias towards small-scale, qualitative, community-based studies. Such studies can provide rich information about the perspectives and experiences of potential customers and can be useful in illuminating ways in which the assumptions of service providers and their models of service provision may be at odds with the people they are trying to serve. However, they are less useful at identifying the scale of particular problems/issues, or the types of intervention that might be most effective (and cost effective) at tackling such issues.

Finally, many studies have adopted an exclusive sampling design, or have not generated samples/undertaken analyses that have allowed comparative analysis across ethnic groups. While some of these studies do report their findings as if they are particular to the group under study, or at least as if these factors distinguish the group from the majority white British, it was rare to find that the researchers had made rigorous comparisons. Indeed, it seems likely that many of the issues identified as barriers to benefit access and a positive customer experience for BME people also play a part in the experience of white British people (particularly those of lower socioeconomic class), albeit to a lesser degree. This is not to say that such factors are unimportant, nor that the routes to addressing such factors would not need to be ethnic-specific. However, if our concern is to confidently identify factors that distinguish the experiences of BME people from the majority white British, then many of the available studies are weak in this regard.



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To gain a better understanding of the issues faced by its' ethnic minority customers, The Pensions Disability and Carers Service (PDCS) commissioned The Centre for Health and Social Care Research to conduct this evidence synthesis. The report makes clear that ethnic minority customers do not form a homogenous group and that lower satisfaction levels with services reported by this group are not caused by ethnicity but by a host of other factors including poverty and language. Issues faced by ethnic minority customers are explored in three sections; personal, local, and PDCS system factors.

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