

# Equality and diversity and older people with high support needs

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**This review adopts a ‘capability-based’ approach to equality, analysing older people with high support needs from different equality groups and highlighting relevant debates associated to equality and diversity.**

Drawing on a range of reports, statistics and conversations with 13 experts, it presents:

- the equality profile of older people with high support needs;
- equality and diversity issues in accessing and experiencing services;
- the gaps in the evidence base;
- a summary of the key debates and recommendations to the Joseph Rowntree Foundation.





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# Executive summary

## Aims and methods

In this review, we use a ‘capability-based’ approach to equality, considering the needs and situations of older people with high support needs from different equality groups and the barriers they commonly face in service provision. We summarise what is already known (and what is not) about the profile, needs and experiences of this group, in terms of age, disability, ethnicity, gender, religion or belief, sexual orientation and poverty. We highlight key debates related to the equality and diversity of this group and suggest ways in which the Joseph Rowntree Foundation’s programme ‘A Better Life’ might contribute to them.

The review draws on reports, abstracts, articles and statistics and our conversations with 13 experts working across the range of equality strands in policy, research and practice. In Appendix 1, we present a separate annotated list of projects, initiatives, networks and organisations which have particular interests, expertise and activities relating to equality and diversity and older people with high support needs.

## The equality profile of older people with high support needs

Initiatives and policy decisions which impact on older people with high support needs cannot be ‘equality neutral’ since we know that this group contains:

- by definition, those who are older and disabled (whether or not they would define themselves as such);
- a higher proportion of women than men;
- a smaller proportion of black people and those from ethnic minority groups than in the general population (but likely to expand rapidly), these groups being disproportionately affected by poor health and many long-term conditions and having support needs that are more likely to be ‘hidden’ from service providers, given barriers to accessing services;
- a larger proportion of people who have religious beliefs than among the general population, beliefs that in many cases will affect the type of care these individuals wish to receive;
- a higher proportion of people from poorer backgrounds, as a result of the association between poverty and ill-health and the greater visibility of their needs to public services;
- a significant minority of lesbian, gay and bisexual people, a group that may be over-represented in the group needing support (as less care may be available from family and some health needs are likely to be greater), but which is more likely to be ‘hidden’ (as people often avoid accessing services or, when they do, do not reveal their sexual orientation for fear of discrimination); and
- a small but increasing group of transgender people, who face particular discrimination.

We also know that there are significant patterns of inequality amongst those caring for older people with high support needs, in both a paid and an unpaid capacity. Younger family carers are more likely to be women and/or black or from ethnic minority communities; many of those caring for this group are themselves older people with support needs of their own; the paid workforce is predominantly female with an increasing number of migrant workers; and poverty can be both a cause and an effect of caring.

## **Equality and diversity issues in accessing and experiencing services**

There has been considerable research on the barriers to accessing services (especially among black and ethnic minority groups, though other groups will often be affected by similar issues). These barriers include:

- difficulty in accessing information (including language barriers for some black people and members of ethnic minority communities);
- difficulty understanding a complex, uncertain and locally varied system;
- stigma, low expectations or lack of confidence in one's right to access services;
- problems in accessing general practitioners and in obtaining an accurate diagnosis, assessment and referral from them and other gatekeepers;
- a lack of appropriate, accessible and attractive provision; and
- housing/financial circumstances and the extent to which private and/or family care may constrain individuals' options.

There has been less research to date on the experiences which diverse older people have of services and their outcomes. Issues for different equality groups may include:

- discrimination in services – from staff, other service users and from the way organisations operate;
- failure of services to take a holistic approach (or to recognise that older people are likely to have different social, cultural, religious/spiritual, emotional or sexual needs), which can have a particular impact on the experiences of older people from equality groups;
- a lack of voice, choice and control for all older people with high support needs but particularly those with dementia or who experience language barriers.

## **Where are the gaps in the evidence base?**

- Few evaluative studies measure and compare experience and outcomes between and within equality groups. This would help us to understand the interplay between different disabilities and conditions.
- Existing poverty measures do not take full account of disability, frailty and long-term illness, and of older people's assets and debts.

- There is a need for more exploration of the different circumstances and expectations of older people with acquired as opposed to pre-existing disabilities, and of older people who are disabled and ill or disabled but in good general health.
- Robust data about the numbers of older black people and people from ethnic minorities in UK care homes and housing with care is lacking.
- There is a lack of research into gender issues in this group (i.e. service users, not carers).
- More evidence is needed about whether and how different service models work for diverse older people with dementia.
- Research findings about older Gypsies and Travellers need to be collated.

## Summary of the key debates

- How can we ensure that the diverse voices of older people with high support needs are heard?
- What does good practice in mixed or mainstream services look like (and feel like)?
- Who is assessing the equalities impact of the options surrounding who pays for care?
- How can we monitor the equality and human rights performance of care providers, especially under increased ‘personalisation’ of care?
- How can diversity in the social care workforce best be promoted and supported so as to provide services that in turn promote equality and human rights?
- Will the Single Equality Bill help protect individuals from ageism, encourage better consultation with older people with high support needs and lever public bodies and government into a more strategic approach, as we hope it will?
- Can a strand-based approach capture the complexity and diversity of older people’s ‘multiple identities’ and can it facilitate better services for older people with high support needs?

## Recommendations to Joseph Rowntree Foundation

Joseph Rowntree Foundation (JRF) is in a good position to promote and provide evidence for these debates by:

- commissioning projects that develop, strengthen and evaluate consultative approaches with diverse groups of older people; and
- identifying, evaluating and disseminating findings about what works for older people, focusing on their experiences and outcomes.

JRF should consider funding specific projects that respond to the evidence gaps we have highlighted. However, it should also take every opportunity to 'mainstream' equality and diversity into the programme, by ensuring that its research and development projects:

- record equality monitoring data which allows for detailed analysis between and within groups;
- use research tools which are consistent and replicable so that we can build on local projects to develop a better national picture of diversity amongst this group;
- strive to recruit as diverse a group of participants as possible;
- focus on the experiences of and the outcomes for older people themselves, using their aspirations, as captured in the 'Keys to a Better Life' (Bowers *et al.*, 2009), as the framework;
- use the language, models and values of 'rights', 'entitlements' and the 'social model' of disability;
- include a systematic consideration of the different equality strands (and the cross-over between them) in both design and analysis; and
- reflect on their learning from an equality and diversity perspective.

# 1 Introduction

The brief for this review was to:

- summarise what is already known – and what is not known – from existing evidence about equality and diversity of older people with high support needs, particularly around poverty, disability, gender, ethnicity and age, but also sexuality and faith; and
- advise on relevant issues, debates, knowledge gaps and concerns in relation to equality and diversity and JRF's new programme, 'A Better Life'.

We were also asked to produce an annotated list of initiatives, organisations, groups and networks that are focusing on these issues and are able to reach out to these groups of older people. This is included as Appendix 1 to the review.

In preparing this review, we:

- spoke to 13 experts in this field, including researchers, practitioners and those involved in policy (these are named in Appendix 2);
- conducted literature searches using Social Care Online, Dementia Knowledge Centre (the Alzheimer's Society) and general internet search engines using a range of terms, and targeted searches of the web sites of relevant organisations; and
- reviewed over 100 articles, report summaries and reports and a number of abstracts (those to which we have referred are listed in the references section at the end of the review).

## What do we mean by 'equality and diversity'?

Following extensive consultation, the Equalities Review (2007) decided to adopt a 'capability-based' definition of equality. This approach recognises that we do not all want exactly the same things (some may value wealth over happiness), but that it is possible to develop a list of the things that matter to people – such as health, self-respect and public participation. It also recognises that we do not all have the same needs (therefore treating everyone identically will not further equality) and that each individual's situation is constrained by barriers, structures and processes. The expansion of real freedoms therefore requires the government and other bodies to actively remove barriers and tackle discrimination, not just stay out of our lives (Burchardt and Vizard, 2007).

*An equal society recognises people's different needs, situations and goals and removes the barriers that limit what people can do and can be. (Equalities Review, 2007, p. 6)*

The equalities legislation protects individuals from discrimination on the basis of their membership of equality groups or 'strands', namely their race/ethnicity, their gender (including transgender men and women), their disability (if they have one), their sexual orientation, their religion or belief (which may include not having a religion) and their age. Public bodies have duties to promote equality and tackle discrimination in a proactive, strategic way, and the forthcoming Single Equality Bill aims to extend these duties across all of the above strands and add a duty to tackle socioeconomic inequalities.

There has, however, been criticism of this 'strand-based approach'. For example, Ward and Bytheway (2008) highlight the 'permeability of these "strands"' and ask what might be involved in 'challenging multiple discrimination'. They argue that 'age connects with the other structural dimensions to which the legislation refers' (pp. 96–7).

Fanshawe and Sriskandarajah (2010) argue that, in an age of 'super-diversity', 'Grouping people according to, say, "ethnicity" in such broad categories seems neither to work particularly well as an analytical tool nor indeed as an expression of felt identity' (p. 29).

With these criticisms in mind, we propose a model in which each of us has a personal identity (which makes us unique) and a 'social identity', which we might view as a package consisting of our race or ethnicity, our gender, our disability (or perhaps our location on a continuum of physical ability, mental health and learning ability), our religion or belief, our sexual orientation, our age and our socioeconomic status.

Understanding that we all have all seven aspects of this social identity can help us to make sense of what Crenshaw (1994) has termed the 'intersectionality' between the strands. Understanding that our personal identity, our social identity and our life experiences (such as being a carer or an asylum seeker or becoming homeless) all combine to make us who we are can help us to avoid the conceptual reductionism of which Fanshawe and Sriskandarajah (2010) warn.

In preparing this review, it also became clear that promoting equality for older people with high support needs is often about upholding their basic human rights.

*Human rights are basic rights to humane dignified treatment and things I should have access to simply because of the fact I am a human being. (Department of Health, 2008, p. 5)*

Human rights link to the concepts of 'equality' and 'diversity' in a number of ways. Firstly, we know that disadvantaged equality groups can be more vulnerable to human rights violations, and one of the 15 rights protected by the UK Human Rights Act (HRA) is the right not to be discriminated against in the enjoyment of the other 14. The Equalities Review (2007) also talks about everyone 'being of equal value – as recognised in human rights principles – and effectively enabled to live a fulfilling life' (p. 16). Significantly, the HRA does not currently apply to people receiving publicly funded services from private sources, though the government has stated its intention to extend it to residents of private care homes whose care is publicly funded (Bowers *et al.*, 2009).

In this review then, we look at whether and how we can usefully apply this model to understanding the situations, needs and constraints of older people with high support needs. We begin by exploring the 'equality profile' of this group, considering whether and why different equality strands might be over-represented amongst older people with high support needs, and how the profile of those who are receiving services may differ from those who are 'hidden'. We then present the evidence regarding the different barriers which these groups may face in both accessing and experiencing positive outcomes from 'services' – namely residential and nursing care; housing with care; and alternative approaches as defined by A Better Life's core programmes.

Defining 'older people with high support needs' is itself problematic: both 'older' and 'high' are used as relative terms, and this begs the question of who decides: medical practitioners, social care workers, older people themselves or their families? Is it about how much support a person needs or how much they are *entitled* to? How much support are *older* people entitled to – enough to make sure they

can wash and eat, enough to prevent a costly admission to care or enough to allow them to participate and contribute? In the review, we take a broad definition; sharing the view of the Equality and Human Rights Commission (2008) that we need to move from a needs-based medical model to a rights-based social model in order to effectively promote the equality of this group.

## 2 The equality profile of older people with high support needs

In this chapter, we look at each equality strand and present the available statistics to provide context and identify any definitional debates, and we give examples of significant patterns, such as differing health needs or changing demographics.

### Age

The older you are, the more likely you are to have high support needs. However, JRF recognises that setting a rigid numerical age definition would be ageist (since not all those over 85 have 'high support needs') and would have a negative equality impact (i.e. it would exclude from the programme younger people with learning disabilities or who are homeless with complex needs, and younger Gypsies and Travellers or refugees who, as a result of disadvantage, may have support needs typical of a much older person).

### Disability

The census asks respondents whether they have 'any long-term illness, health problem or disability which limits activities or work': in the last census, nearly 80 per cent of women aged 85 and over and approximately 70 per cent of men in this age group said that they did (Office for National Statistics, 2005a). Older people with high support needs will meet the Disability Discrimination Act definition of disability in that they will have one or more impairments which have 'a substantial and long term effect on their ability to carry out day-to-day activities'.

However, many of this group will not see themselves as 'disabled', especially those who have acquired their condition in later life, and not all of those who have pre-existing disabilities will be ill or have 'high support needs' as they age. There seems to be a knowledge gap regarding the different experiences and outcomes of these groups and regarding older people's perceptions of their 'disabilities'. Those who have spent most or all of their lives as disabled people are more likely to have accumulated disadvantage (through poorer educational and employment opportunities), and are thus at greater risk of poverty as they reach retirement, than those who have acquired disabilities later in life. They may find that some of their benefits and services are changed or withdrawn when they reach 65. Some, particularly those with learning disabilities or severe mental health conditions, may have spent much of their lives in institutions, or certainly their earlier adult lives prior to the policy shift in 'community care'.

It is not possible, in this review, to do justice to all the types of impairment or long-term conditions that commonly affect older people. Dementia is a key issue for this group and for our review. The Alzheimer's Society (2007) estimates that one in six people over 80 has some form of dementia, and it anticipates a steady growth in the number of those with the condition in the next few decades. The very nature of the condition (often compounded by myths and stereotypes) can mean that this group is particularly vulnerable to discrimination and human rights infringements. We also know that people with dementia from black and ethnic minority backgrounds face particular barriers to accessing diagnosis, treatment and care (e.g. Seabrooke, 2009; Hashmi, 2009) and that those caring for a same-sex partner

with the condition can face additional challenges to having their status and relationships recognised by services and courts (Manthorpe, 2003). There is currently very little evidence on how personalisation or the independent living agenda would work for people with dementia, and the Royal College of Psychiatrists (2009) has identified a need to collect, develop and evaluate examples of good practice in working with older people from black and ethnic minority communities who have dementia and other mental health problems.

Other disabilities and long-term conditions, though perhaps not as prevalent as dementia, can raise particular equality issues. It has been estimated that 4.6 per cent of people over 75 are deafblind, a group that faces particular barriers in terms of access to information and involvement in social activities (Sense, 2008). This figure may be a significant under-representation as it excludes adults with profound learning disabilities or multiple disabilities and older people in nursing homes. This reminds us that many older people will have more than one disability or long-term condition and that there will be interplay between these 'multiple conditions'. People with learning disabilities experience higher rates of dementia (King, 2004); some of those with dementia will also be deaf (according to research by Professor Alys Young; see Appendix 1); and so on.

Improvements in medical treatment have extended the life expectancy of many disabled people and, as a result, we are witnessing emerging communities of ageing disabled people. Half of people with Down's syndrome will now survive into their 50s or beyond (King, 2004) and Dougan *et al.* (2004) highlight an increasing population of older people with HIV, as medical treatment improves and more older people are diagnosed HIV positive.

Disability and ageism intersect in a number of key ways for older people with high support needs. The 'social model' of disability (in which it is the barriers that prevent disabled people from participating that disable them) and the associated concepts of 'disabled rights', 'independent living' and 'rehabilitation' are rarely applied to older people. Older people are generally still viewed through the 'medical model' (in which the focus is on the impairment) and the discourse is one of dependence, care, dignity, frailty and pity. This is partly as a result of the way in which older people's and disabled people's campaign groups have developed (Priestley and Rabiee, 2002) and partly a result of ageist assumptions about the inevitability of decline and low expectations about participation, independence or contribution from older people with high support needs (Bowers *et al.*, 2009; Centre for Policy on Ageing, 2009).

## Gender

In 2003, there were 100 women for every 40 men within the 85 and over age category (Office for National Statistics, 2005a). On average, men die younger than women (with life expectancy in 2006 standing at 81.5 years for women compared with 77.2 years for men), and the average woman spends 17.7 years with a limiting chronic illness or disability compared with 14.6 years for the average man (Office for National Statistics, 2009). Given gender differences in life expectancy, it is perhaps not surprising that, in 2007, 61 per cent of women aged 75 and over were living alone compared with 34 per cent of men in the same age group (Office for National Statistics, 2009).

There are different gender patterns around the types of health conditions that older people experience. For example, men are much more likely than women to die prematurely as a result of coronary heart disease, and morbidity and mortality from virtually all cancers that are not sex specific are consistently higher in men (Men's Health Forum, 2008). Older women have a much higher risk of osteoporosis than their male peers, and of subsequent fractures as a result of falls, which are a major cause of 'high support needs' in the UK. One in two women and one in five men will suffer a fracture after the age of 50, mainly due to osteoporosis (National Osteoporosis Society, undated).

The marital status of older men has been found to be strongly associated with health-related behaviours, with divorced and never-married men, for example, reporting the highest levels of drinking

and smoking. Many older men are unwilling to consult their GPs, and men (especially those from working-class backgrounds) are much less likely to access social clubs or day centres (Arber *et al.*, 2002).

Gender differences in education, employment and roles within the home are much starker for today's generation of older people, and this can result in different needs (e.g. women may have little experience of dealing with finances or men may lack key domestic skills). As a result of a lifetime gender pay gap, older women are considerably poorer than older men, and the oldest are poorest of all (Age Reference Group on Equality and Human Rights, 2005). Domestic violence will have affected the health status and needs of a significant minority of older women and may continue to be a feature of older people's intimate relationships (Blood, 2004).

Despite these significant gender differences, there has been little analysis of the implications from a policy perspective and few studies have analysed gender differences in access to or experience of services by older people with high support needs (Equal Opportunities Commission, 2007).

## Ethnicity

The age profile of black and minority ethnic communities in the UK is still relatively young compared with the white British population. In 2001, 1.4 per cent of the total minority ethnic population of England and Wales was aged 80 and over, compared with 4.6 per cent of the white British population (Policy Research Institute on Ageing and Ethnicity, 2008). However, a dramatic increase in the number of older people in the UK from black and ethnic minority groups is predicted: for example, census data shows that in 2001 over a tenth of the total minority ethnic population was aged between 60 and 79 (Policy Research Institute on Ageing and Ethnicity, 2008), and this does not include those who have arrived in the UK in the past decade.

People over 65 from 'Asian' and 'Black' ethnic categories are disproportionately affected by poor health and high rates of limiting long-term illness and have an increased risk of becoming dependent on others at an earlier age as a result of disability (Age Concern, 2007a). We also know that some ethnic groups experience higher rates of some long-term conditions, for example people from South Asian backgrounds are generally twice as likely to have a diagnosis of diabetes (Department of Health, 2005) and have considerably higher than average rates of premature death from coronary heart disease and strokes (Harding *et al.*, 2008).

Some groups of minority ethnic people experience particular barriers in accessing services as a result of their life experiences. Although there has been little specific work on older Gypsies and Travellers, research conducted on the health needs of this whole community (Van Cleemput *et al.*, 2004; Southern and James, 2006) suggests that poverty, poor living conditions on many sites and problems accessing health care are likely to result in a high incidence of early-onset health problems. Studies of older refugees also suggest that people in their 50s and 60s often have health problems typical of much older people as a result of trauma and physical injuries experienced in country of origin combined with stress, poverty and barriers to accessing health care in the UK (Older Refugees Programme, 2008).

## Religion and belief

In the 2001 census, people over 50 were more likely than younger people to state that they had a religion: 6.7 per cent of the older age groups said they had no religion, compared with 14.8 per cent of the total population, and the rate was significantly higher among older men than older women. Of those aged 50 and over, 83 per cent described themselves as Christian; the next three largest groups were Muslims (1 per cent), Hindus (0.7 per cent) and Jews (0.6 per cent) (Office for National Statistics, 2005b).

Meeting religious needs might include providing food prepared in a certain way; celebrating religious festivals and holy days; providing space to pray or worship; arranging transport to places of worship; making appropriate funeral arrangements (for those who do not have a religious belief as well as

those who do); organising access to pastoral care, books, music and artefacts; or considering aspects of physical design (for example, orthodox Jews do not permit the active use of electricity on the Sabbath, so lifts, lighting and doors need to run automatically; Institute for Jewish Policy Research, 2002).

## Poverty

The recent report of the National Equality Panel (2010) shows how economic inequalities cumulate throughout life, reinforced by unequal pay, limited opportunities and systematic discrimination, to generate very different resources in retirement and inequalities in health and mortality in later life. We know that caring (for both children and adults) has a significant impact on the finances and health of carers, and this is a key reason why older women are at a greater risk of poverty than older men (Burholt and Windle, 2006).

Income, housing status and occupation are all linked to health outcomes for older people. Those over 50 who are living in council accommodation, on low incomes and/or with histories of manual or unskilled professions are much more likely to report long-term limiting conditions (Office for National Statistics, 2005a). As these factors are also likely to affect older people's access to care and support, we can assume that people from poorer socioeconomic backgrounds are likely to be over-represented amongst the group of older people with high support needs.

Price (2008) has highlighted some significant gaps in the research on poverty and older people to date. Firstly, none of the poverty measures she reviews take account of the differences that frailty, disability or long-term illness makes to the experience of poverty for older people or their carers. Secondly, very little attention has been given to how we measure assets and debts within the resources of older people – yet the issue of 'asset rich, cash poor' older people is increasingly significant in the policy debates about the future funding of social care.

Older people with high support needs in the lower-middle income bracket are likely to be experiencing the hardest financial impact from the current system of means-tested payment for social care (Resolution Foundation, 2008). Low earners are more likely than higher earners to be care service users and/or carers and are more likely than those receiving state support for care to be home-owners. Women are over-represented in this group and, although the report does not explore other equality strands, it is quite likely that older people from black and ethnic minority groups will also be over-represented since we know that, as a group, they are more likely to have lower incomes and lower equity values in their homes (Care and Repair, 2005). The Commission for Rural Communities (CRC) (2006) demonstrates that there is an urban–rural dimension to older people's poverty. Older people living in areas that are geographically remote from social care services are vulnerable to fuel poverty and isolation and can, in particular, experience barriers to access as a result of limitations of service choice and transport options as well as the need to travel long distances.

Other groups of older people living in extreme poverty include older homeless people and asylum seekers. As a result of their life experiences and lack of access to health and housing, these groups often experience complex health issues in their 50s or 60s that are typical of much older people (Blood, 2003; Pannell, 2005; Older Refugees Programme, 2008).

## Lesbian, gay, bisexual and transgender people

In the absence of accurate data, the government is currently working on the basis that between 5 and 7 per cent of the UK population is lesbian, gay or bisexual (Age Concern, 2008). It is likely that older lesbian, gay and bisexual people are over-represented amongst those needing formal support as they are less likely to have children, more likely to be out of touch with their birth families and their own children, and 2.5 times more likely than heterosexual older people to be living alone (Age Concern, 2006).

Research evidence suggests that the older lesbian, gay or bisexual population has a higher incidence of certain health conditions and health-related behaviours than the general older population, including higher levels of smoking, drinking, mental health problems, cervical and breast cancer amongst women, and HIV infection amongst men (Musingarimi, 2008a).

It is also likely that many older people in this group who do have support needs are 'hidden' from service providers and policy-makers since their fears and experiences of discrimination can act as a barrier to seeking help. In addition, often individuals in this group, when they do access services, decide not to disclose their sexuality (Musingarimi, 2008b). The current generation of older lesbian, gay or bisexual people may have experienced incarceration and 'corrective' treatments in the past, and some will have moved to the UK from countries which continue with punitive or medical approaches to their sexuality.

Older transgender people constitute another emerging ageing community as, although previous generations have experienced gender 'dysphoria', treatments and surgery have been made available only relatively recently. Research conducted by Whittle *et al.* (2007) estimate that 7 per cent of the transgender population are over 61, and 4 per cent of those who underwent gender reassignment surgery in England in 2005/6 were aged 60–74 (Age Concern, 2008). This group face considerable prejudice and, in social care, may have various needs around their personal care, for example, the need to shave, catheterise or find appropriate gender clothing in the right size (Age Concern, 2007b).

## Who is caring for older people with high support needs?

We know that some equality groups are over-represented amongst those who provide care to older people with high support needs, both in a paid and in an informal capacity. Younger family members caring for older relatives are more likely to be women, and Bangladeshi and Pakistani people are three times more likely than white British people to provide care (Carers UK, 2009).

Although 70 per cent of those receiving family care are over 65, 11.5 per cent of those providing care are over 65, and those providing high levels of care are twice as likely to be 'permanently sick or disabled' as those not caring (Carers UK, 2009). Older spousal carers are more likely to be men, are more likely to be from white or Indian backgrounds (Buckner and Yeandle, 2005) and are more likely to be from lower socioeconomic groups, reflecting the higher levels of disability and the reduced opportunity to buy in formal care (Lloyd, 2008).

Himmelweit and Land (2008) have highlighted the fact that 80 per cent of paid social care workers are women. Poor pay and conditions have led to problems with recruitment and retention, and migrant workers (mostly women) are increasingly plugging the gap. In 2006, 16 per cent of registered care assistants and home care workers in the UK had been born overseas (Liverpool Social Care Partnership/Oxfam/Migrant Work Workers North West, 2008).

The ethnic diversification of the UK workforce brings language skills, knowledge of different cultures and faiths and visible diversity to many care settings, which may encourage black and minority ethnic groups to access services and improve their experiences and outcomes when they do so. However, achieving this whilst protecting workers from discrimination at the hands of service users and other staff requires an organisational approach – including good management and clear strategies to promote equality.

## Services for older people with high support needs: how can ‘social identity’ affect access, experience and outcomes?

In this section, we look particularly at the services which are the focus of the three core programmes of ‘A Better Life’, i.e.

- residential and nursing care;
- housing with care;
- alternative approaches (which we take to mean ‘models and services that support older people within their homes’ for the purposes of this review).

Since JRF has commissioned a separate review entitled *Access and Diversity in Housing with Care* (King and Pannell, 2010), we will concentrate on the other two core programmes.

### What do we know about the take-up of services by equalities groups?

Our knowledge in this area can be summarised as follows:

- It has been estimated that, in 2004, 410,000 older people lived in care homes in the UK (Office of Fair Trading, 2005).
- Most care home residents are aged 85 and over (Office of Fair Trading, 2005).
- It is estimated that 75 per cent have a ‘severe disability’ (Office of Fair Trading, 2005).
- It is reported that 64 per cent of people living in care homes have a form of dementia (Alzheimer’s Society key statistics; [www.alzheimers.org.uk/site/scripts/documents\\_info.php?categoryID=200120&documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200120&documentID=341)).
- A third of those with dementia live in care homes, while the remainder live in the community (Alzheimer’s Society, 2007).
- In 2009, 41 per cent of care home residents were found to be paying for all their care (Counsel and Care, 2009).
- Women made up nearly three-quarters of those over 65 receiving home care in 2008/9 (Health and Social Care Information Centre, 2009a).
- In 2001, 23 per cent of women aged 85 and over lived in communal establishments, compared with 12 per cent of men of this age (Office for National Statistics, 2009).
- According to Community Care Statistics for England (Health and Social Care Information Centre, 2009b), 4 per cent of those over 65 ‘receiving services’ are from non-white backgrounds.
- According to Age Concern (2008), 3 per cent of the total population of those over 65 are from black or minority ethnic backgrounds.

- There is a lack of robust quantitative data about the numbers of minority ethnic older people in the UK who are living in care homes (Mold *et al.*, 2005) or in housing with care (Jones, 2006).

## What are the barriers faced by equality groups accessing services?

### Information and rights

There has been a strong focus in the literature on barriers to accessing services for black and minority ethnic older people with high support needs. A recurring finding is that this group are at particular risk of not knowing what services exist or how to start accessing them (e.g. SubCo Trust, 2007; Housing Corporation, 2008; Jones, 2008). As the title quote of Manthorpe *et al.*'s (2008) article plainly states, 'if we don't know about amenities, we cannot seek them out'.

Given the complexities, future uncertainties and local variations in the provision of social care (e.g. Beresford, 2008; Coalition on Charging, 2008), understanding the system can be challenging for anyone. It follows that someone who does not speak much English or has poor literacy, a sensory impairment or a learning disability, for example, will be at a particular disadvantage. If advocates or 'cultural mediators' are not available, it can be very difficult for many older people to make informed decisions about their housing and care options (Manthorpe *et al.*, 2008).

Research into access to housing advice services (Shelter, 2007) found that people from black and ethnic minority communities are generally more likely to ask friends or family or to approach a community group for advice than to contact the council or a specialist advice provider. Understanding of the system will, of course, vary within and between ethnic and class groups: as Moriarty (2008) points out, many older African Caribbean women have worked in UK health and social care services, whereas a recently arrived immigrant may not know where to start.

Chahal and Ullah (2004) have concluded that, in the case of some black or minority ethnic older people, language barriers account for part, but not all, of the problem. The failure of many services to promote themselves effectively and in a way that is relevant to ethnic minorities has also been blamed (Jones, 2008; Manthorpe *et al.*, 2008). This often seems to be caused by a belief that local demographics do not require such an approach (Manthorpe, 2004) or the assumption that ethnic minority communities 'will look after their own' (Gandhi and Bowers, 2008).

There is evidence that patterns of intergenerational care-giving are starting to change in some communities (Housing Corporation, 2008), yet older people who strongly believed they would be looked after by their children are often poorly informed about other options (Gandhi and Bowers, 2008). As Patel and Traynor (2006) point out:

*The idea of seeking external help when problems arise is still regarded by many elders from different ethnic backgrounds with shame and guilt and a sign of family failure or worse their own. (p. 8)*

This is not solely an issue for older people from South Asian backgrounds, as a Birmingham-based study concludes, 'Older Irish people tend not to seek help even about health problems' (McGee *et al.*, 2008, p. 5).

Low expectations of services or a lack of confidence in accessing them can be an issue for any older person; however this may be compounded for some migrants and refugees by ambiguity over their citizenship rights. Hussain and Bagguley (2005, p. 418) argue that some older Pakistanis 'feel they lack the "full citizenship" of their sons and daughters'.

## Referral, diagnosis and assessment

GPs are key gatekeepers in accessing health and social care services, yet we know that some groups of older people, such as refugees and Gypsies/Travellers, can experience particular difficulties in even getting registered at a practice (Van Cleemput *et al.*, 2004; Older Refugees Programme, 2008). Stereotypes and assumptions can further reduce the likelihood of some groups getting a timely and accurate diagnosis. For example, Murray *et al.* (2006) found that primary care professionals were reluctant to talk about depression to older Asian and Caribbean people because they thought that these patients would not want to consider the possibility that they might be depressed. Black and minority ethnic people with dementia may also be at particular risk of misdiagnosis, and in particular of being labelled as 'mentally ill' and treated with (inappropriate) medication (Daker-White *et al.*, 2002).

The failure of GPs to refer people to other non-medical services (e.g. Manthorpe *et al.*, 2008) and the failure of those providing care to see beyond the presenting problem and to ensure that other primary care needs (such as chiropody or eye tests) are met was a recurring theme in the literature and our consultation. Black and minority ethnic older people were felt to be at particular risk of this as a result of stereotyping, language barriers and a lack of clarity surrounding their rights or a lack of confidence in asserting them. Common stereotypes that can hinder appropriate treatment and referral include all Irish people being heavy drinkers (McGee *et al.*, 2008); black people not wanting counselling (Chahal and Ullah, 2004); people from some minority communities being fatalistic and therefore not being interested in improving their conditions (Mir, 2008); and the myth that all minority ethnic communities will 'look after their own' (Gandhi and Bowers, 2008). However, assessors do need to be aware that people from different cultural backgrounds may not share 'Western' models of ageing in terms of family, independence, privacy, mental health or care. As a result, they may have different ideas about what constitutes a need and how needs should be prioritised (Moriarty, 2008).

'Assessment' for social care is increasingly focused on eligibility, costs, services and tasks (Beresford, 2008; Equality and Human Rights Commission and Cordis Bright Consulting, 2008) and less about understanding holistic needs within the context of individual (and group) histories. Only 40 per cent of respondents to the Commission for Social Care Inspection (2008a) survey of lesbian, gay and bisexual service users reported 'coming out' at their last assessment or review, and only 24 per cent felt that their needs were adequately considered at their last assessment. Fewer than half of the older black and minority ethnic people surveyed by the Commission for Social Care Inspection (2008b) felt that their needs were adequately considered at their last assessment. The lack of choice, voice and control of many older people with high support needs in their own care planning has been highlighted by Bowers *et al.* (2009). Older people who are also poor, from a minority background, lesbian, gay or bisexual or suffering from dementia or other mental health issues are likely to be in an even weaker position to make or assert informed choices.

Individuals who do not have access to good information about services, or who find 'preventative' services increasingly difficult to access (unless they can afford to pay for them personally) (Rankin, 2005), are at a particular risk of an unplanned and sudden move to a care home following a health and/or carer crisis. The Office of Fair Trading (2005) estimates that carer stress is the main trigger in 38 per cent of all admissions of older people to care homes. This is a particular risk for people from black or minority ethnic communities and their families (Mold *et al.*, 2005).

## Availability and perceptions of options

The lack of 'culturally appropriate' care options has been identified as a key barrier for older people from minority ethnic and/or faith groups. Key issues can include the proximity of care homes or housing with care schemes relative to the geographical 'hub' of a minority community; the lack of culturally and/or religiously appropriate catering arrangements; the mix of staff and residents; the types of activities

on offer; and language barriers. Ironically, not all care homes are fully accessible, especially when we consider the role which physical design can play in helping people with dementia, learning disabilities or sensory impairments to move around safely and independently. According to the Commission for Social Care Inspection (2008a), just 7 per cent of care homes for older people and 8 per cent of domiciliary care agencies have carried out any specific work around sexual orientation.

The quality of existing housing, the availability of unpaid care and the financial situation of older people with high support needs can strongly influence the options available to them, and we know that these factors can vary by equality strand. Some groups of older people will not have their own homes to start with, such as those with a learning disability (King, 2004) and those who are homeless (Blood, 2003; Pannell, 2005). Gandhi and Bowers (2008) point out that an increasing number of older homeless people are from black and minority ethnic backgrounds – often they have become homeless as their legal rights to the home have passed to the next generation and the family home has become overcrowded.

Older people from some equality groups are at particular risk of living in housing that is unfit (whether poorly insulated, overcrowded or in need of repair), inaccessible or in a remote or unsafe area. Poverty is clearly the key factor here, though the interaction with other ‘strands’ can influence this too. Muslims are most likely to live in overcrowded housing (Office for National Statistics, 2005b), older people in rural areas are more vulnerable to fuel poverty (Commission for Rural Communities, 2006), refugees tend to live in some of the worst housing in the most deprived neighbourhoods (Older Refugees Programme, 2008) and some older lesbian, gay, bisexual or transgender people are forced to leave their homes as a result of harassment (Organisational Development and Support/Stonewall Scotland, 2004).

The availability and willingness of a family member, friend or partner to provide care and/or advocacy can also vary by equality group. Older lesbian, gay or bisexual people may be less likely to have younger family and friends who are in a position to provide care. People with learning disabilities may find themselves in ‘mutual care’ arrangements with ageing parents or many find themselves without family support following the death or health crisis of a caregiver. Many minority ethnic communities place a strong emphasis on intergenerational care, though research has found that many older people from such communities do not receive the level of care they had expected (or others frequently assume they receive) from their families (SubCo Trust, 2007; Housing Corporation, 2008; Gandhi and Bowers, 2008). Some older people with high support needs will be living amongst extended families but with many of their needs unmet.

Older people or their families who can afford to buy in support privately should have more options open to them. However, the plight of older people who are ‘asset rich but cash poor’ was highlighted in our literature review and discussions. Although equity release has offered a solution for some, research has suggested that some groups of older people from black or minority ethnic communities are particularly reluctant to get involved in loan schemes (whether to fund care or adaptations) because of pressures regarding inheritance, a general mistrust of financial institutions or, in the case of Muslims, a lack of Sharia-friendly options (Housing Corporation 2008).

The Coalition on Charging (2008) argues that local authority charges for care are pushing many older people into greater poverty and worse health outcomes. It reports that many people with medium and high support needs have had to manage without vital services (often relying more instead on family and friends) or to reduce spending on heating, food or social activities. Even people who are paying for care often say that they have little choice over what is provided and how, where, when and by whom. Bowers *et al.* (2009) explain that self-funders in care homes are further disadvantaged in that they rarely have access to assessment, independent review, advice or support. There is currently little evidence regarding this group of self-funders in terms of numbers, demographics, experiences or outcomes.

## Experience of care services

There has been less research to date on the experiences which diverse groups of older people have of services and the subsequent outcomes. For example, we found little research comparing the experiences and outcomes of men and women in care homes, of older black and minority ethnic people in specialist provision or mainstream services or of individuals from black or minority ethnic communities with different types of disability.

The national survey of home care users aged 65 and over (Health and Social Care Information Centre, 2009a) found that 23 per cent of white respondents were extremely satisfied with their home care compared with 17 per cent of the Asian ethnic group and 16 per cent of the black ethnic group. This pattern was consistent with the previous year's findings.

Bowers *et al.* (2009) take a significant step by actively seeking out older people in care homes and asking them about their aspirations. The findings do not provide much evidence regarding the experiences of different equality groups; rather they show just how much work remains to be done to meet the basic human rights of all older people in care homes and to give them voice, choice and control.

The 'keys to a good life' identified by Bowers *et al.* (2009) through their direct work with older people in care homes are relevant to all older people, whatever their gender, ethnicity or sexual orientation. However, we can imagine that some of these might become more pertinent for an older person who is in some way 'different' from 'the norm' within a service. 'Feeling safe and secure' may have a different meaning for those who have experienced or are experiencing discrimination, while being accorded 'respect for your sexual life, identity and relationships' is much less likely for a gay man or lesbian. 'Maintaining friendships and contact' may require more proactive support from staff in the case of those from a minority faith group, and a 'sense of self' and other people's knowledge and respect of that may be very different if you come from a different ethnic group, class or gender from most of the people living and working in the home.

## Discrimination in services

In the Commission for Social Care Inspection (2008b) survey of black and minority ethnic care service users, 13 per cent of the older respondents reported that they had experienced discrimination whilst using services (and a further 9 per cent were uncertain), compared with 53 per cent of respondents under 65 (with a further 18 per cent of this age group uncertain). Some also reported specific experiences in the survey, which they might have defined as discrimination, but then answered 'no' when specifically asked if they had experienced discrimination.

Ward and Bytheway (2008) remind us how difficult and subjective it can be to decide whether or not to describe a particular incident as 'discriminatory' – much discrimination is experienced as subtle and even ambiguous. Discrimination can operate in so many different ways – subtle or overt; direct or indirect; individual or institutional – in a setting such as an older people's home. Discrimination can result in exclusion (through not communicating information), stereotyping (deciding what kinds of activities someone will or will not want to do) or desexualisation (by assuming that the old and disabled are not sexually active). In addition, care workers who render individuals invisible (by failing to ask them what they would like), assume that they know best (by making decisions on individuals' behalf) or define a norm and place others outside it (as a man, gay person or black or minority ethnic person) are practising discrimination.

*I have experienced racism in the services I use ... yes I experience racism from fellow service users, the staff tell me to take no notice. (Older person in care home)*

*You feel they don't want to talk with you, they just want to come in and out. They might be like that anyway to everyone, I don't know. But I feel they really don't want me to be there, so it could be racism. They are all white and English so far, so maybe. I haven't said anything to them, you don't know what might happen if you do. (Older home care user, Commission for Social Care Inspection, 2008b, pp. 31–2)*

The stress for those who decide to hide their sexual orientation for fear of discrimination can be considerable and professionals who do not recognise the existence or significance of partners or 'families of choice' can have an important negative effect on the quality of care, individuals' relationships (Musingarimi, 2008c) and the way in which bereavement and end-of-life support is provided.

## **A holistic approach**

A common theme from the literature and consultation is that the provision of care has become reduced to a series of tasks (see, for example, Bowers *et al.*, 2009). The focus is on basic bodily care and, within this, as one frontline worker put it, 'No one is asking "How would you like me to bathe you?"'. This is a very personal matter, yet, at the same time, whom we want to bathe us and how we want them to go about it is influenced by our gender, sexuality, culture, disability, age and religion.

Minority groups seem to be at a particular risk of having their emotional, social, spiritual/religious and sexual needs overlooked and are likely to experience a disproportionate negative impact where services take a one-size-fits-all approach. Older people from black and minority ethnic communities in Bradford emphasise the importance of having their emotional needs met (Cattan and Giuntoli, 2010). Age Concern (2006) has questioned whether it is possible to effectively assess someone's social contacts, interests and relationships if their sexual orientation is overlooked. Dementia Voice (2000) has criticised the majority of mainstream care homes for failing to meet the spiritual needs of people with dementia. Bowers *et al.* (2009) observe that people with sensory and/or cognitive impairments seem to be at particular risk of exclusion from social activities. Percival (2010) describes how fellow residents in extra care housing can sometimes react negatively to those who have dementia and/or are visibly frail.

The need to fit in, feel at home and not have to keep explaining your needs recurs in conversations and articles about services that are targeted at a certain group (e.g. Institute for Jewish Policy Research, 2002; Bartlett, 2006). The National Evaluation of Partnerships for Older People's Projects (Personal Social Services Research Unit, 2009) found that, although projects generally struggled to engage older people from black and minority ethnic communities, they did become involved 'when there was the opportunity to secure funding to set up culturally specific groups and activities, such as lunch clubs, befriending and exercise groups, and advocacy services' (p. 69). Similarly, Age Concern Camden has been successful in engaging with older gay men and lesbians because it began by setting up much needed social groups for them and could then start to address other needs.

## **Voice, choice and control**

Good communication between service provider and service user is essential if voice, choice and control are to be achieved. There may be a number of different barriers for different equality groups, including language (for service users and/or workers) or dialect (e.g. Patois or Irish), dementia, learning disability, stroke or hearing impairment.

Bowers *et al.* (2009) have questioned the extent to which older people in care homes have any meaningful input into their own care planning. Even small daily decisions, such as what to wear and when to bathe, are often taken by staff, and a risk-averse culture means that residents (especially those with dementia) are generally not encouraged to do anything that might be 'risky'.

Feeling able to complain about a service is a basic right within voice, choice and control, yet this can be challenging for older people with high support needs, who may wonder whether anyone will take them seriously or whether they will receive a worse service as a result of complaining. There may even be physical barriers. As one older black person living in a care home who had experienced verbal abuse said, 'If you want to complain you have to go to the office and complain, and that's difficult to go to them' (Commission for Social Care Inspection, 2008b, p. 33). We spoke to an advocate working with older black and minority ethnic people who raised concerns about what happens to those who do not have relatives or independent advocates. For example, she explained that one of her clients, who had been admitted to hospital, had not eaten anything, since he had not been given the assistance to eat at meal-times that he needed, despite her instructions on admission.

## Outcomes

Most discussion of 'outcomes' for older people with high support needs has focused on financial costs or savings and the needs of services. However, several key publications in recent years have called for, and started, the development of outcomes frameworks which focus on older people's needs and rights (Equality and Human Rights Commission and Cordis Bright Consulting, 2008; Bowers *et al.*, 2009).

The Social Care Institute for Excellence (2008) argues that, although older people from different ethnic backgrounds broadly want the same outcomes from services, they may prioritise different outcomes (such as religious or cultural needs) over others. In other words, things may need to be done differently to ensure that the needs of diverse older people are met.

# 3 Conclusion

## Summary of the knowledge gaps we have identified

Throughout the review, we have identified the following apparent gaps in the evidence base. We summarise these here and refer the reader to the relevant page.

- Evaluative studies that measure and compare experiences and outcomes among different equality groups from different models of care provision are generally lacking (p. 20).
- There is a need to take account of the effect of frailty, disability or long-term illness on the experience of poverty for older people or their carers and a need to devote more attention to how we factor assets and debts into measurements of poverty among older people (p. 14).
- There is a lack of robust quantitative data about the numbers of minority ethnic older people living in UK care homes and extra care housing (and where those who are not but have high support needs are living and what alternative services they are receiving) (p. 17).
- A knowledge gap exists regarding the different experiences and outcomes of older people with acquired and pre-existing disabilities and older disabled people who are ill and those who are not. There also does not seem to have been much focus on older people's perceptions of their 'disabilities' (p. 11).
- There is a lack of studies comparing the experiences and outcomes of older men and women living in care homes and analysing the implications of the gender differences among older people with high support needs from a policy perspective (p. 13).
- There is very little evidence on how personalisation or the independent living agenda would work for people with dementia, and the Royal College of Psychiatrists (2009) has identified a need to collect, develop and evaluate examples of good practice in working with older people from black or minority ethnic backgrounds who have dementia or other mental health problems (p. 12).
- Older Gypsies and Travellers are mentioned briefly in a number of local and national studies, but this information does not seem to have been drawn together anywhere (p. 13).
- There is currently little evidence regarding self-funders in terms of numbers, demographics, experiences or outcomes (p. 19).

## Key debates and recommendations for JRF

Bowers *et al.* (2009) argue that ‘there is currently no visible discussion going on around rights, equality and opportunities for this population of older people’ (p. 7). We hope that our annotated list shows that a considerable number of projects, organisations and initiatives, both nationally and locally, aim to identify, advocate for, understand or provide good care services to diverse older people with high support needs. However, in terms of national debate, the act of bringing ‘equality and diversity’ and ‘older people with high support needs’ together in the same sentence seems to be a fairly radical departure. A key challenge is to ensure that the (very quiet, according to Bowers *et al.*, 2009) voice of older people with high support needs is listened to by national and local policy-makers. Within that we also need to ensure that the diverse voices of this group are sought out and heard.

The debate around specialist versus mainstream provision for minority groups is well rehearsed. Yet, as Manthorpe *et al.* (2008) point out, older people from black and minority ethnic background ultimately just want services that meet their needs (which, non-coincidentally, the local voluntary sector often does very well). Factors such as local demographics, the presence or absence of a grass-roots voluntary sector and economies of scale around interpreters and catering will inevitably influence the extent to which specialist provision is feasible or sustainable. There is a danger, when trying to identify good practice in working with diverse older people, of ending up with a list of specialist projects mostly based in London or other large cities, which risks further fuelling the sense that diversity ‘isn’t a problem’ anywhere outside these urban centres. There is undoubtedly more work to be done to identify what good practice looks like (and feels like) within mainstream services and to capture the views of staff and service users in projects where diversity appears to be supported.

The significant changes afoot within social care pose challenges and opportunities for diverse older people with high support needs. As debates continue to rage over who will pay for care in the future, it will be vital to continue to raise awareness and gather evidence about the differential impacts of alternative models on different equality groups (Keen, 2008). Individual budgets may well be the best solution for a lesbian, gay or bisexual older person (Musingarimi, 2008c) or for a black or minority ethnic older person living in a rural setting but, as an advocacy worker we spoke to pointed out, ‘if the budget holder has dementia or is severely disabled or ill, who is going to check that their needs and human rights really are being met in this situation?’ The Care Quality Commission (2009) has made a positive start by building measures of providers’ performance on equality and human rights into its broader assessments of user experience and outcomes rather than in a stand-alone indicator on policies and processes. The next challenge will be to evaluate this approach carefully and work out how this can be applied in practice to direct payments, individual budgets and the broader personalisation agenda.

In the parallel review of workforce issues for ‘A Better Life’, Manthorpe (2010) leaves us with the question ‘Which organisational and management characteristics and approaches foster effective staff–resident interactions and the implementation of successful practices?’ This is particularly pertinent within the context of increasing ethnic diversity in the workforce. How do the diversity of the team, the extent to which a diverse team is effectively managed and the extent to which the workplace culture promotes equality influence the promotion of equality and human rights for the older people who use the service?

The Single Equality Bill contains a number of significant opportunities: to protect individual older people with high support needs from discrimination on the grounds of age; to lever public bodies into better consultation with this group; and to demand of local and national government a more strategic approach to ensuring that the needs of diverse groups are met and that the impact of policies (such as local charging policies) on both age and socioeconomic status is considered.

There are undoubtedly challenges for a strand-based model in capturing the complexity of the multiple forms of discrimination which older people with high support needs encounter. However, this review has, we hope, shown that there are some stark patterns of inequality and some significant shared needs for the different equality groups within this broad and heterogeneous group. If a relatively simple

model, such as that of 'social identity', backed up by the Single Equality Bill, can prompt and support service providers and policy-makers to identify and tackle the barriers faced by many older people with high support needs (who fit into at least two disadvantaged groups within the 'strands'), then it can surely be said to work. At the same time, however, it is the task of researchers to test this model by developing the evidence base on the differences within and across the equality groups and the interplay between and betwixt multiple conditions and different forms of discrimination.

JRF is in a good position to promote and provide evidence for these debates by:

- commissioning projects that develop, strengthen and evaluate consultative approaches with diverse older people with high support needs; and
- identifying, evaluating and disseminating findings about what works for diverse older people, focusing on their experiences and outcomes.

JRF should consider funding specific projects which respond to the evidence gaps we have highlighted. However, JRF should also take every opportunity to 'mainstream' equality and diversity into the 'A Better Life' programme, by ensuring that its research and development projects:

- record equality monitoring data that allows for detailed analysis between and within groups;
- use research tools which are consistent and replicable so that we can build on local projects to develop a better national picture of diversity amongst this group;
- focus on the experiences of and the outcomes for older people themselves, using the 'Keys to a Better Life' as the framework;
- use the language, models and values of 'rights', 'entitlements' and the 'social model' of disability;
- include a systematic consideration of the different equality strands (and the cross-over between them) in both design and analysis; and
- reflect on their learning from an equality and diversity perspective.

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# Appendix 1

## Annotated list of organisations and initiatives

### Introduction

This list presents a selection of national, regional and local initiatives which have a particular interest in older people with high support needs and equality and diversity, at a policy, research and/or service delivery level. We have sought to include organisations that are already in contact with diverse groups of older people so that these might be a starting point for research or consultation projects. Key publications are included in the references section; however, we include here practical resources, such as toolkits and checklists.

This list is intended to be not a comprehensive directory but rather a starting point to develop connections and share best practice. It has not been within the scope of this review to audit or evaluate these projects, so this list is intended not to showcase 'good practice' but rather to give the reader a feel for the types of initiatives relevant to equality and diversity and older people with high support needs.

We present these initiatives by strand, even though this has created some challenges where they are working across strands (e.g. projects working with black and minority ethnic people who have dementia are presented under the dementia section). Where initiatives cross over a number of strands, we have put these in the 'cross-strand' section at the end.

### Ethnicity

The **Afiya Trust** ([http://afiyatrust.org.uk/index.php?option=com\\_frontpage&Itemid=1](http://afiyatrust.org.uk/index.php?option=com_frontpage&Itemid=1)) is a London-based, black and ethnic minority-led, second-tier organisation with a nationwide remit to reduce inequality in health and social care provision for racial groups. The trust launched a new manifesto on the well-being of black and minority ethnic people on 16 March 2010. *Achieving Equality in Health and Social Care: A Framework for Action* is based on a series of consultations with 500 service users, practitioners and carers nationwide, and provides a detailed review of existing and future research.

**Age Concern** and **Help the Aged** convened an 'initial learning meeting' on older Gypsies and Travellers in Derby in February 2009. Staff from local branches of these organisations heard from the Derbyshire Gypsy Liaison Group and others who work with and/or have conducted research into Gypsies and Travellers and discussed practical issues facing older people from these groups. The report of the meeting and the contact details of those who attended can be found at [http://eurolinkage.org/AgeConcern/Documents/Older\\_Gypsies\\_and\\_Traveller\\_Report.pdf](http://eurolinkage.org/AgeConcern/Documents/Older_Gypsies_and_Traveller_Report.pdf).

**Age Concern Scotland** ([www.ageconcernandhelptheagedscotland.org.uk/our\\_work/policy/research](http://www.ageconcernandhelptheagedscotland.org.uk/our_work/policy/research)) has worked in partnership with race equality organisations in Scotland to launch Age Concern BMEEG (Black and Minority Ethnic Elders Group) Scotland. The group aims to bring together older people from diverse backgrounds with the aim of promoting equality of citizenship and opportunity and better access to housing, health, social work and education through culturally sensitive services. Age Concern Scotland also worked with the University of Stirling on a research project into elder abuse and older black and minority ethnic people called 'They put up with it – what else can they do?'

**Age UK Regional Office for Yorkshire and the Humber** has developed a project entitled 'Later Matters' as part of the Tackling Race Inequalities Programme. This project has developed a progress tool and good practice guidelines for organisations on identifying issues and overcoming barriers to providing

accessible and appropriate health and social care services for black and minority ethnic elders in the region in consultation with relevant groups. Organisations have received training in using this tool to support other organisations in their service reviews.

**Alison Bowes** at **University of Stirling** is the lead for a Department of Health-funded research project called 'Dignity and Respect in Residential Care: Issues for Black and Minority Ethnic Groups'. The study aims to recruit older people from a number of different minority ethnic groups and from a range of care homes across the UK. The study will focus on these participants' experiences of their care home settings and was due to complete in August 2010.

**BME Elders Forum** was established in 2002, with support from Age Concern England, and is open to voluntary and community organisations (local, regional or national) with a stated interest in and experience of working with black and minority ethnic elders and interested professionals. Age UK continues to support the forum, which exchanges information and experience between service providers and identifies policy issues and shared interests, with the aim of improving the lives and hearing the voice of older black and minority ethnic people.

In the West Midlands, **brap** ([www.brap.org.uk](http://www.brap.org.uk); a national equalities and human rights charity) has launched a project called Later Matters, which is funded by the Tackling Race Inequalities Fund. Working in partnership with Age UK, the initiative aims to help increase the levels of older people from black and minority ethnic backgrounds who participate in civic participation, volunteering and decision making forums in the region.

The **Department of Health** (2002) *Developing Services for Minority Ethnic Older People: The Audit Tool* ([www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4002762](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002762)) includes a diagnostic questionnaire and an action plan template, both of which are intended to act as practice guidance for all councils with social services responsibilities, and other local stakeholders who want to make a positive step to real service changes for minority ethnic older people.

**Hanover Housing Association** ([www.hanover.org.uk](http://www.hanover.org.uk)) commissioned a piece of research (by Kalyani Gandhi-Rhodes) into multicultural services and design with extra care. This reviewed the association's (and other providers') extra care housing schemes which were specifically commissioned to meet the needs of older people from ethnic minority groups.

**HOPDEV (Housing and Older People Development Group)** (2006) has developed *At Home: Audit Tool for Housing and Other Related Services for Older Minority Ethnic People* ([www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/Topics/browse/HousingOlderPeople/BMEGroups/?parent=976&child=1556](http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/Topics/browse/HousingOlderPeople/BMEGroups/?parent=976&child=1556)). This toolkit has been designed to help ensure that housing and related services take account of the needs of black and minority ethnic elders. It will be particularly useful to service commissioners and providers, as well as older people from these groups.

The **Leeds Older People's Forum** ([www.opforum.webeden.co.uk/#/bme-focus-group/4515427243](http://www.opforum.webeden.co.uk/#/bme-focus-group/4515427243)) is a group of 120 voluntary sector organisations working with older people across the city. The group has a number of initiatives relevant to equality groups and issues, including the Leeds BME Elders Focus Group, which aims to improve the involvement of voluntary organisations for older black and minority ethnic people in the development of older people's services in Leeds. Leeds Gypsy and Traveller Exchange (GATE; [www.opforum.webeden.co.uk/#/leeds-gate/4525616805](http://www.opforum.webeden.co.uk/#/leeds-gate/4525616805)) is a member of the forum and provides an advocacy service and runs an older people's group, which includes social activities, and is open to Gypsies and Travellers in the area aged 45+.

**Nehemiah United Churches Housing Association Ltd** ([www.nehemiah-ucha.co.uk](http://www.nehemiah-ucha.co.uk)) is part of a consortium of five local authorities in the West Midlands (Birmingham, Dudley, Sandwell, Walsall and Wolverhampton) and the Department of Health Housing Learning & Improvement Network, which has commissioned research into the ways older black and minority ethnic people access housing for older people, including extra care. This research is being carried out by the University of Birmingham. Nehemiah has a housing with care scheme with a diverse mix of residents, including those with a range of disabilities.

**Nubian-Life** provides community based care to older black Caribbean people with high support needs in Hammersmith and Fulham. It provides day care to people with medium to high needs (many of whom have dementia or other mental health conditions and complex needs), a lunch club for those who need medium levels of care (typically those who are recovering from strokes, falls or surgery), a drop-in centre for more active over-50s and an advocacy service, which provides intensive one-to-one support where older people are facing crises and do not have close family or friends to support them.

The **Older Refugees Programme** was a two-year joint programme between Age Concern England, the Refugee Council ([www.refugeecouncil.org.uk](http://www.refugeecouncil.org.uk)), Age Concern London and the Association of Greater London Women (AGLOW). Operating between 2006 and 2008, it aimed to highlight the issues and concerns that older refugees have about their circumstances and daily lives in the UK, and to raise awareness among service providers and statutory agencies of this particularly marginalised group of older people. A literature review, conference report and working paper are still available for download from their web site.

The **Policy Research Institute on Ageing and Ethnicity** (PRIAE; <http://www.priae.org/>) aims to make a difference towards an improved quality of life for all black and minority ethnic elders. It does this by producing information, carrying out studies with targeted policy and service developments and engaging minority elders and organisations, for example through its Minority Ethnic Elders' Policy Network.

The **SubCo Trust** ([www.subco.org.uk](http://www.subco.org.uk)) is a specialist service provider for Asian elders and their carers in the London Borough of Newham. The trust provides a range of day care services to those over 55 years from the subcontinent, focusing on those who are frail, isolated and/or housebound. It has a block contract with Newham Social Services to provide 25 places, five days a week, which must be filled by older people who meet Fairer Access to Care Services criteria as having critical or substantial impairments. They also provide a meals service and befriending and have provided a number of joint initiatives with social services for mixed groups of older people. They have also undertaken research and consultation into the needs of Asian elders in Newham.

## Lesbian, gay, bisexual and transgender

**Age UK's** (formerly Age Concern and Help the Aged) national Opening Doors initiative was set up some eight years ago in response to the observation that older lesbian, gay and bisexual people were not accessing Age Concern services. Opening Doors offers support to local services on working with their local older lesbian, gay and bisexual communities, works in partnership with other national organisations and develops resources, including *The Whole of Me*, a resource pack on meeting the needs of older lesbian, gay and bisexual people living in care homes and extra care housing. At a local level, many Age Concern offices have taken initiatives to promote their services to this community. For example, Opening Doors in Central London, managed by Age Concern Camden, won Big Lottery funding to appoint two full-time workers, one to work with older lesbians and one to work with older gay men. Age UK and the International Longevity Centre – UK have also recently successfully secured funding from Pfizer and inspired to develop a national LGBT Intergenerational Project, bringing together older and younger lesbian, gay, bisexual and transgender people.

**Anchor** Housing Trust ([www.anchor.org.uk/About-Anchor/Diversity](http://www.anchor.org.uk/About-Anchor/Diversity)), one of the largest providers of residential care, sheltered care and other forms of housing and care for older people, has established a lesbian, gay, bisexual and transgender tenant group. The group aims to help make Anchor a safe and welcoming environment for lesbian, gay, bisexual and transgender tenants and staff, to provide support and guidance for other tenants and staff, to act as a sounding board on issues of relevance to this group and to benchmark activities and share best practice with other associations.

**Communities Scotland/ODS Ltd** have developed a checklist for housing and housing support providers, called 'Ensuring equality for older LGBT people in Scotland' ([www.fitra.co.uk/pubs/Ensuring\\_Equality\\_for\\_Older\\_LGBT\\_People\\_in\\_Scotland.pdf](http://www.fitra.co.uk/pubs/Ensuring_Equality_for_Older_LGBT_People_in_Scotland.pdf)). The checklist was developed from the

findings of a research project commissioned by Communities Scotland, Age Concern Scotland and the Equality Network. It contains sections on raising awareness and ensuring access to services, consistency of service delivery, listening to service users, confidentiality and sharing information, housing management and providing support.

**Elizabeth Price** at the **University of Hull** has been involved in a number of research projects focusing on older lesbian, gay and bisexual people with high support needs (in particular those with dementia) and their carers.

**Equality Network** ([www.equality-network.org](http://www.equality-network.org)) and **Age Concern Scotland** ([www.ageconcern-scotland.org.uk](http://www.ageconcern-scotland.org.uk)) work in partnership to engage older lesbian, gay, bisexual and transgender people to participate in shaping law and policy through the Your Scotland project.

**Future Years** (Regional Forum on Ageing, Yorkshire and the Humber) and **Age UK Regional Office** have recently launched a toolkit ('It's not just about sex') for providers of services to older lesbian, gay, bisexual and transgender people in Yorkshire and the Humber, which draws on the experiences of this group in the region.

**Greenwich Council** and **Greenwich NHS Teaching PCT** have developed a joint Strategy for the Health and Social Care of Older Lesbians, Gay Men and Bisexuals (2008–2011), in conjunction with the (voluntary sector) Metro Centre. The strategy gives definitions; outlines the historical, social, cultural, legal and policy contexts for these groups; and summarises shared issues for them in accessing health and social care services. It discusses a number of practical ways in which services can be made more accessible to these groups, such as communication, training, targeted marketing and the commissioning of specialist services. The council and trust recognise that they now need to identify resources to implement their action plan; however, the document seems to be a very positive start to a strategic, partnership approach. They have also done an equality impact assessment of the strategy, which considers the impact of it across all the other strands ([www.greenwich.gov.uk/NR/rdonlyres/FE674FAA-7903-451D-ABC4-D1D39A8D599C/0/DraftStrategyCareOlderLGBTMay08.pdf](http://www.greenwich.gov.uk/NR/rdonlyres/FE674FAA-7903-451D-ABC4-D1D39A8D599C/0/DraftStrategyCareOlderLGBTMay08.pdf)).

The **National Osteoporosis Society** has produced a factsheet on transsexualism and osteoporosis, which can be downloaded from [www.nos.org.uk/NetCommunity/Document.doc?id=386](http://www.nos.org.uk/NetCommunity/Document.doc?id=386).

**Press for Change** is the main campaigning organisation and a good source of information on transgender issues. It has, for example, compiled a list of links to all the key documents on transgender health and social care, including those by the Department of Health ([www.pfc.org.uk/node/613](http://www.pfc.org.uk/node/613)).

**Stephen Whittle** is the most prominent UK researcher into transgender issues, and he has undertaken research for Age Concern on older transgender people, as well as research into the discrimination faced by transgender people of all ages from health and social care services.

**Stonewall Housing** and **Age UK** have jointly convened an Older LGBT Housing Group, to identify the housing needs and aspirations of lesbian, gay, bisexual and transgender people in later life and to propose creative solutions. The group is multiagency, made up of older people, housing providers and voluntary and public sector bodies. It looks at the broadest range of housing needs and solutions, from private homes through to sheltered housing and residential care. The group is now seeking to develop a national role from its original London-wide remit.

The **Terrence Higgins Trust** has recently completed a review of issues for older people who are HIV positive. The project, which is called Fifty Plus, was funded by the Joseph Rowntree Foundation, and a key finding was that older migrants living with HIV experience particular difficulties compared with other older people living with HIV.

## Gender

**AGLOW** (Association of Greater London Older Women) is a voluntary organisation of older women in London. Its objectives are to bring together older women to discuss issues affecting them and therefore raise their collective voice and counter age discrimination, racism, sexism and homophobia. It organises

conferences on topical issues, produces a quarterly newsletter and, through assertiveness training and sessions on communication, boosts women's confidence and empowers them to make their voices heard. Recent seminars have addressed the housing needs, community care, health needs and mental health needs of black and ethnic older women, Irish older women, older refugee women and latest developments about older women in the EU.

The **Centre for Research on Ageing and Gender** (CRAG) is based in the Sociology Department of the University of Surrey ([www.crag.surrey.ac.uk/index.html](http://www.crag.surrey.ac.uk/index.html)). It focuses specifically on the interconnections between gender and ageing, conducting research on how the transitions in later life (e.g. from employment to retirement, marriage to widowhood, health to functional impairment and independent living to residence in a care home) have different meanings and implications for older women and men, and on the ways in which policy should take into account these differences. A current focus is on research to optimise sleep quality among older people living in the community and care homes (SomnIA).

Following the highly successful Mensheds scheme in Australia, Age Concern launched its first 'Men in Sheds' initiative in Mitcheldean, where older men (over 55) will help to renovate hand tools for despatch to poor communities in Africa ([www.shedworking.co.uk/2008/05/men-in-sheds-age-concern.html](http://www.shedworking.co.uk/2008/05/men-in-sheds-age-concern.html)).

**Men's Health Forum** ([www.menshealthforum.org.uk/](http://www.menshealthforum.org.uk/)) is a charity that provides an independent and authoritative voice for male health in England and Wales. It aims to tackle the issues and inequalities affecting the health and well-being of men and boys and it does this by lobbying, research, training, providing information and advice to men and partnership working. The forum's key areas of work are physical activity, cancer, workplace health, mental health and access to primary care.

## Religion and belief

**Amina**, the Muslim Women's Resource Centre ([www.mwrc.org.uk/](http://www.mwrc.org.uk/)), has produced *Helping Bereaved Muslims*, a booklet which summarises some of the beliefs and customs of Muslims around death, funeral rites etc., in order to inform counsellors and those supporting bereaved Muslims. Amina provides a range of other services to Muslim women in Scotland, including a helpline, information, relationship counselling to individuals and couples; advice and advocacy and befriending support.

**CSAN** (Caritas Social Action Network; [www.caritas-socialaction.org.uk/](http://www.caritas-socialaction.org.uk/)) is the umbrella organisation of charities with a Catholic ethos, providing professional social care within the UK. The organisation has a number of projects relevant to older people with high support needs, including a directory of services provided by the Catholic community to older people, an audit of residential homes and outreach services provided by the Catholic voluntary sector for this group, and a project on dementia and spirituality which includes a DVD and training sessions.

**Jewish Care** ([www.jewishcare.org/](http://www.jewishcare.org/)) provides care homes and a range of other services to older Jewish people with high support needs across London and the south-east of England. This includes specialist projects aimed at those suffering dementia and holocaust survivors/refugees. Their Jewish Care Direct Helpline provides a single point of access to all their services.

The **Leveson Centre** (formerly the Leveson Centre for the study of Ageing, Spirituality and Social Policy) is part of a Christian foundation. It runs seminars, lectures, a web site and an occasional news service to support the study, reflection and exchange of ideas and information of those interested in developing the understanding and expression of older people's spirituality. The centre has produced a resource list on the spiritual needs of older people, which includes links to many downloadable publications and includes sections on people in care homes and people living with dementia (<http://rps.gn.apc.org/leveson/resources/study-resourcelist.htm>).

**Nightingale** ([www.nightingalehouse.org.uk/](http://www.nightingalehouse.org.uk/)), originally known as the Home for Aged Jews, is a care home in Clapham, London, which provides care on both a respite and long-term basis to older Jewish people. The project has three residential care and three nursing care units (including one for

people with dementia) and is licensed to provide care to 253 residents. It also provides day care and a range of social activities. The Centre for Social Justice has recently announced that it will use the home as a good practice case study in its forthcoming report on elder care in the UK.

**Sikh Elders Neighbourhood Network** is part of the Touchstone Project, Leeds ([www.touchstone-leeds.co.uk](http://www.touchstone-leeds.co.uk)). It aims to bring together Sikh people aged 55 and over who may be isolated and improve their health, well-being and independence. The project is culturally sensitive to the needs of Sikh elders and delivered by Punjabi-speaking staff and volunteers. The project provides activity classes, a luncheon club and one-to-one support through its volunteer-run befriending service.

## Poverty

**Counsel and Care** ([www.counselandcare.org.uk/](http://www.counselandcare.org.uk/)) is an organisation that provides advice to older people (in their own homes, in sheltered housing and in care homes) on a range of community care issues, including finding and paying for care, welfare benefits and hospital discharge. The organisation has for some time now been highlighting the financial concerns of older people regarding social care through its campaigning, policy and research work. It is also exploring alternative, community-based approaches to supporting older people with high support needs as part of a parallel review for the Joseph Rowntree Foundation.

The **Gifted Housing Service** ([www.helptheaged.org.uk/en-gb/AdviceSupport/HousingChoices/GiftedHousing/](http://www.helptheaged.org.uk/en-gb/AdviceSupport/HousingChoices/GiftedHousing/)) was set up over 35 years ago by Help the Aged to support people who find themselves on their own in later life and have concerns about managing the responsibilities of home ownership. Help the Aged has now merged with Age Concern, and the new charity, Age UK, is committed to continuing this unique service throughout England and Wales. Donors to the Gifted Housing Service donate their property to the charity and, through a legal agreement, receive the following benefits:

- maintenance, repairs and external decoration to their property organised and paid for by the charity;
- council tax, water rates and building insurance all covered by the charity;
- essential upgrading and improvement to the property where necessary;
- an annual contribution towards gardening costs;
- heating and hot water system maintained or renewed if necessary;
- regular visits from a care coordinator and housing manager;
- help in arranging care and support at home;
- advocacy and support at times of crisis or serious ill health;
- contributions towards care costs, including residential care, should this become necessary.

**Joseph Rowntree Foundation**, working in collaboration with local authorities, the equity release industry and voluntary bodies and on advice from the Department for Work and Pensions, launched a pilot scheme in January 2010 in three local authority areas to help asset-rich but income-poor older people to stay in their own homes. The scheme, which provides independent financial advice and access to the Home Cash Plan, has been designed to ensure that older people are getting all the financial help to

which they are entitled, to allow them to draw relatively small amounts of money and to minimise their risk of losing pension credit as a result.

The **New Policy Institute** ([www.npi.org.uk/index.htm](http://www.npi.org.uk/index.htm)) is an independent think-tank which has research experience and interests in poverty (especially the impact of policies on low-income households), older people and social care. It is keen to develop work around these themes.

The **Resolution Foundation** is an independent research and policy organisation which works to improve outcomes for the UK's 14 million low earners. Over the last two years, the foundation has conducted an extensive programme of research and policy work in the field of long-term care for older people, with a particular focus on the mixed markets in both funding and care provision. The foundation has produced reports which map the long-term care market, and which suggest what a future architecture for a care and support system could look like. More recently, in 2010, the organisation published a report that examines the use of equity release as a means for asset-rich, income-poor low earners to meet their care costs. The Resolution Foundation continues to work as part of the Care & Support Alliance to ensure that social care reform is a priority for the new government ([www.resolutionfoundation.org/research\\_long\\_term\\_care.html](http://www.resolutionfoundation.org/research_long_term_care.html)).

The **UK Coalition on Older Homelessness** ([www.olderhomelessness.org.uk/](http://www.olderhomelessness.org.uk/)) is a lobby group of housing and homelessness agencies concerned with raising the profile of older homeless people in the UK. The coalition is based at Homeless Link with funding from Help the Aged and the Housing Associations Charitable Trust. It has produced various research reports and good practice guides, which are available from its web site.

## Dementia and other mental health conditions

**Alzheimer's & Dementia Support Services** (ADSS; [www.alzheimers-dementia.org.uk](http://www.alzheimers-dementia.org.uk)), based in Kent, runs an Early Intervention Project that, working through primary care practices, aims to promote dementia awareness, early diagnosis and take-up of services amongst people aged 65–75, including those from the South Asian communities, in north-west Kent. For example, the project has produced a culturally relevant information leaflet and invited older Asian patients with memory problems to make an appointment with their GP or practice nurse.

The **Care Quality Commission** (CQC) is working to develop ways of bringing the voice of older people with dementia into its inspections. The commission has been reaching out to local dementia groups and partner organisations and looking into ways of involving people with the early stages of dementia in their Experts by Experience programme (see web site for more detail: [www.cqc.org.uk/getinvolved/inspectionsandvisits/expertsbyexperience.cfm](http://www.cqc.org.uk/getinvolved/inspectionsandvisits/expertsbyexperience.cfm)). In this programme, older people with experience of using services and/or carers conduct conversations with other people who use services and staff as part of a care home inspection. Where people with dementia are less able to communicate, inspectors use the Short Observational Framework for Inspection (SOFI) in care homes inspections. SOFI was developed by Bradford University in conjunction with one of CQC's predecessor commissions: the Commission for Social Care Inspection (CSCI). CQC is currently working with Bradford University to develop a more flexible observational tool to help assess essential standards of quality and safety. It will be used not only in care homes but in other services such as hospitals and independent health care settings where people with dementia, learning disabilities and language impairments are in receipt of care.

**Professor Alys Young at Manchester University** is leading a three-year research project on dementia and the deaf community called 'Overcoming obstacles to the early identification of dementia in the signing deaf community'. This project, funded by the Alzheimer's Society, is about facilitating early identification of dementia amongst deaf people who use British Sign Language, and developing effective care which meets their unique needs. The research team includes DCAL (the Deafness Cognition and Language Research Centre at University College London), City University London, the Social Research with Deaf

People group and the Dementia and Ageing Research group at the University of Manchester, and the Royal Association in Aid of Deaf People.

**Dementia Voice** ([www.dementia-voice.org.uk/index.htm](http://www.dementia-voice.org.uk/index.htm)) is the specialist dementia services development arm of Housing 21. It is responsible for the management and development of specialist care provision, research and training. Dementia Voice is committed to evidence-informed practice and to contributing to the knowledge bank of evidence-based research on design, technology and service delivery around older people and mental health. Research projects have explored the themes of marginalised groups, spirituality, consultation, rehabilitation services and very sheltered housing for people with dementia.

The three-year **Ethnic Minority Dementia Advocacy Project** was established by Westminster Advocacy Service for Senior Residents (WASSR; [www.wassr.org/dementia.htm](http://www.wassr.org/dementia.htm)) and the Dementia Advocacy Network (DAN) with a Department of Health grant. The project aimed to raise awareness about dementia and dementia advocacy amongst black and minority ethnic communities (and their organisations) and to raise awareness about the needs of black and minority ethnic older people with dementia. Although funding ran out in July 2009, the evaluation report contains useful guidance on how best to reach out to vulnerable members within minority ethnic communities. It also concludes that building trust, relationships and an understanding of what works is a slow process and that demonstrating outputs and outcomes in the short space of time that funders often require them can be challenging.

**Dementia UK** ([www.fordementia.org.uk](http://www.fordementia.org.uk)) is the national charity supporting Admiral Nurses, who are specialist mental health nurses working primarily within the National Health Service to provide practical and emotional support to those caring for people with dementia. Aware that, in the past, relatively few people from black and minority ethnic communities were accessing the service, Admiral Nurse Vincent Goodorally worked with South West London and St George's Mental Health NHS Trust ([www.swlstgtr.nhs.uk](http://www.swlstgtr.nhs.uk)) and other stakeholders to raise awareness of dementia amongst these communities in Kingston. This Care Services Improvement Partnership (CSIP)-award-winning project delivered training to GPs and other key professionals on the barriers, issues and needs of black and minority ethnic people with dementia. Vincent is now working with other admiral nurses to roll this approach out nationally.

**JackDawe Sahara Team**, Nottingham City Social Services, was launched in 2005, as an extension of the city's award-winning JackDawe home care service for people with dementia. The Sahara scheme works specifically with older Asian people with dementia. The scheme provides personal care but works with service users to try and reinvolve them in as many aspects of their daily lives as possible, including personal care, domestic support, social, religious and leisure activities.

**Meri Yaadain** ([www.merियाadain.co.uk/index.html](http://www.merियाadain.co.uk/index.html)) is a dementia support project working with South Asian communities in Bradford. The name (developed to respond to the fact that there is no word for dementia in most South Asian languages) means 'My Memories'. The project uses roadshows, radio programmes and newsletters to engage the community and provides home visits, support group meetings and telephone support to older people with dementia and their carers. Find out more about the project and view a DVD of the experiences of some of their service users and carers at the web site.

The **National Development Team for Inclusion** is working with the Alzheimer's Society to develop and implement a shared vision of life 'beyond services' for people living with dementia, and for those who support them. This project includes a training and development programme for volunteers, family carers, staff and people living with dementia ([www.ndti.org.uk/what-we-do/client-groups/older-people.aspx](http://www.ndti.org.uk/what-we-do/client-groups/older-people.aspx)). It aims to raise awareness and develop new ways of providing support that increase choice and control and greater opportunities for inclusion in family, community and civic life.

The **Royal College of Psychiatrists** ([www.rcpsych.ac.uk/](http://www.rcpsych.ac.uk/)) produced a detailed review of service provision to black and minority ethnic older people (*CR156: Psychiatric Services for Black and Minority Ethnic Older People*) in September 2009. One of its agreed actions from this was to set up a working group within the Faculty of Psychiatry of Old Age to link in with other interesting organisations, share good practice and evaluate and promote new research in this area.

## Learning disability

Five **local Age Concern** branches, with financial support from two charitable trusts, were involved in a two-year pilot programme (from 2005 to 2007) to raise awareness and develop practice in providing support and services for older people with learning disabilities. The Age Concern branches involved in the programme developed small-scale initiatives addressing the social and emotional needs of older people with learning disabilities and their older family carers. These projects included research, consultation work and service reviews exploring key issues such as 'mutual caring', the impact of 'double discrimination' around age and learning disability and person-centred approaches to working with older people with learning disabilities and their families. A report of the learning from the pilot programme is available via the national Age Concern web site ([www.ageconcern.org.uk/AgeConcern/learning\\_disabilities.asp](http://www.ageconcern.org.uk/AgeConcern/learning_disabilities.asp)).

The **Foundation for People with Learning Disabilities** (FPLD; part of the Mental Health Foundation) undertakes research, promotes the rights of people with learning disabilities and works to improve services. The Older Families Initiative builds on their earlier Growing Old with Learning Disabilities programme and aims to explore issues and best practice for people with learning disabilities who are living with older parents or relatives and providing mutual care. A range of resources, such as DVDs, good practice examples, project evaluations, information packs and useful links, are available online, including a report focusing on the specific issues for such families from the Pakistani community. FPLD has recently completed a project on mutual caring within older families, which is featured on the front page of their web site ([www.learningdisabilities.org.uk/](http://www.learningdisabilities.org.uk/)). This includes planning books for older family carers and for people with learning disabilities living with them.

The **Valuing People Support Team** has produced *Being a Carer and Having a Carers Assessment*, a pack of information, tools and stories to support people with learning disabilities who are themselves carers to get the support they need. This can be downloaded from the Older Families Initiative web site above.

## Sensory impairment

'Touching Lives – across the generations' ([www.deafblindscotland.org.uk/index.php?option=com\\_content&view=article&id=127:touching-lives-project&catid=36:about-us&Itemid=53](http://www.deafblindscotland.org.uk/index.php?option=com_content&view=article&id=127:touching-lives-project&catid=36:about-us&Itemid=53)) is an initiative being run by **Deafblind Scotland**, with National Lottery funding. It provides older (50 years and over) deafblind people the opportunity to develop their skills and become trainers in dual sensory impairment, disability awareness facilitators, speakers on deafblindness, and representatives on committees.

**Deafblind UK's** Black and Ethnic Minorities project aims to raise the levels of deafblind awareness within black and minority ethnic communities in London and has been specifically targeting older people, as the incidence of deafblindness is highest amongst this group. With Big Lottery funding, the project has worked to identify individuals and link them into services, and to raise awareness of deafblindness amongst these communities. Although the funding ran out in July 2009, the project continues to provide awareness raising sessions and will shortly publish an evaluation of the work.

**MHA** (originally Methodist Homes) is a major provider of not-for-profit care homes, housing and support services for older people. MHA also has a significant research portfolio, which includes work on dementia, spiritual care (including older men's spirituality) and the needs of older black and minority ethnic people. Two MHA care centres (Moor Allerton, Leeds, and Mayfields, Ellesmere Port, Cheshire) are currently taking part in a study on dementia and sight loss undertaken by researchers at Bradford University and commissioned by the Thomas Pocklington Trust, with funding from the Joseph Rowntree Foundation. This study will assess the sight loss sensitivity of models of dementia care and identify the needs of this group, given that so many of the current methods of communication and orientation rely on sight and visual design features.

**Sense**, the national charity for deafblind people, offers a number of resources specific to older people. These include the Seeing Me toolkit on recognising dual sensory loss in residential or domiciliary care and a factsheet on hearing and sight loss in older people ([www.sense.org.uk/publicationslibrary/allpubs/older](http://www.sense.org.uk/publicationslibrary/allpubs/older)).

The **Thomas Pocklington Trust** ([www.pocklington-trust.org.uk/](http://www.pocklington-trust.org.uk/)) has produced a number of research reports and occasional papers about older people with sight loss and older people who have both sight and hearing loss. They also run two extra care housing projects and one registered care home for older people with sight loss

## Cross-strand initiatives

**Age UK** is implementing a three-year 'Older People & Human Rights' project, funded by Comic Relief, and working in partnership with the BIHR (British Institute of Human Rights) and four local Age Concern branches. The project aims to empower older people to use human rights principles and tools to influence practice/service provision in their local areas. The project has produced a research and mapping report on older people and human rights. An evaluation report on the project will be produced in year 3, and the project is due to finish in September 2011.

The **Equality and Diversity Forum** ([www.edf.org.uk/](http://www.edf.org.uk/)) is a network of national organisations committed to equal opportunities, social justice, good community relations, respect for human rights and an end to discrimination based on age, disability, gender and gender identity, race, religion or belief, and sexual orientation. It can use its electronic networks to identify local, regional and national initiatives on topics related to equality and diversity.

The **Housing Learning & Improvement Network (LIN)** ([www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/](http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/)) is part of the Department of Health Care Networks and is the national network for promoting new ideas and supporting change in the delivery of housing, care and support services for older and vulnerable adults, including people with disabilities and long-term conditions. It has produced a range of resources on diverse older people, including those with dementia, learning disabilities and physical disabilities, and those from black and minority ethnic backgrounds.

The **National Institute for Health Research (NIHR) School for Social Care Research (SSCR)**; ([www.sscr.nihr.ac.uk](http://www.sscr.nihr.ac.uk).) is currently commissioning expert reviews on research methods in the field for completion in summer 2010. Among the areas covered are research with black and minority ethnic populations in adult social care (led by Professor Gary Craig, University of Durham) and sexualities in adult social care research (led by Dr Liz Price, University of Hull).

The Older People's Programme (OPP) joined forces with the National Development Team on 1 April 2009 to create **NDTi** (National Development Team for Inclusion) – placing its work on improving the life chances of older people within a broader context of equality, inclusion and citizenship across the life course ([www.ndti.org.uk/what-we-do/client-groups/older-people.aspx](http://www.ndti.org.uk/what-we-do/client-groups/older-people.aspx)). One of the new organisation's key current projects involves qualitative research with the Office for Disabilities South East Regional Initiative ([www.odi-seri.org/](http://www.odi-seri.org/)) to demonstrate and measure the impact of new approaches in increasing the voice, choice and control of older people living in (or at risk of moving into) residential and/or nursing care.

# Appendix 2

## List of people we spoke to during our consultation

We would like to thank the following individuals for supporting this review with their time, views and expertise:

Amanda Ariss, Chief Executive, Equality and Diversity Forum

Jazz Browne, Capacity Building Manager, Nubian Life

Stephen Burke, Chief Executive, Counsel and Care

Karen Culshaw, Strategy Officer, Care Quality Commission

Vincent Goodorally, For Dementia

Baroness Sally Greengross, Chief Executive, ILC-UK

Emily Holzhausen, Director of Policy and Public Affairs, Carers UK

Deborah Klee, independent consultant

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Professor Jill Manthorpe, King's College London

Jenny Pannell, independent consultant

Meena Patel, independent consultant

Taskin Saleem, Chief Executive, SubCo Trust

Antony Smith, Development Officer (Equalities and Human Rights), Age Concern and Help the Aged

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## About the ILC-UK

The International Longevity Centre – UK (ILC-UK) is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. It develops ideas, undertakes research and creates a forum for debate. The ILC-UK is a registered charity (no. 1080496) incorporated with limited liability in England and Wales (company no. 3798902).

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