Improving health and social care support for carers from black and minority ethnic communities

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Equality
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Key messages

1 Although support for carers generally remains inadequate, the experience of black and minority ethnic carers tends to be compounded by structural disadvantage and the marginalisation of 'race' equality within social policy

2 Mainstream organisations can and should be responsive to the specific needs of black and minority ethnic carers, but the low take-up of mainstream services is often attributed to the characteristics of carers rather than to institutional barriers and culturally inappropriate support

3 The black and minority ethnic voluntary sector has a key role in addressing the needs of carers from black and minority ethnic backgrounds, but it experiences marginalisation, inadequate funding and lack of strategic representation

4 Social policy acknowledges that service users and carers should be at the centre of policy development, but opportunities for meaningful participation have remained minimal for black and minority ethnic carers

5 The assumption that black and minority ethnic carers are a homogeneous group overlooks the diversity between and within communities and the ways in which ethnicity and disability intersect with other aspects of carer and service user identity.

Who is a carer?

A carer is someone who provides ongoing unpaid care for a child, relative, friend, partner or neighbour who cannot manage on their own due to disability, serious illness, mental health difficulties, frailty or substance misuse. Children and young people under eighteen, whose lives are significantly affected by caring responsibilities, are usually referred to as 'young carers'.
(Adapted from The Princess Royal Trust for Carers, 2010)

Black and minority ethnic

The term 'black and minority ethnic' is used here to refer to communities racialised and minoritised in relation to the local population on the basis of their 'racial,' 'ethnic' or national origin. This includes established groups (e.g. African, Asian, African-Caribbean), new migrant communities (e.g. people from Eastern European countries), refugee and asylum seeker communities, transient communities (e.g. the Traveller community) and groups often referred to as 'invisible minorities' (e.g. the Irish community).
(Jayasree Kalathil, unpublished)

Introduction

The government estimates that the number of carers in the UK will rise from six to nine million over the next twenty years as a result of increased life expectancy and more people surviving with impairments (DH, 2008). While this projection includes black and minority ethnic communities, there is a lack of baseline data regarding the numbers, role and experiences of carers from these communities. However, the low take-up of mainstream services suggests that many lack support and only come to the attention of services when they reach crisis point (NBCCWN, 2008a).

This briefing paper draws attention to the experience of black and minority ethnic carers in the context of mainstream service provision and recent policy developments such as the National Carers Strategies, service user and carer involvement and the personalisation agenda. It acknowledges that marginalisation is often a consequence of lack of support for both carers and black and minority ethnic communities in health and social care. The paper highlights the diversity of carers from these ethnic backgrounds and the multifaceted impact of discrimination.

The hidden cost of caring	1

- More than 80 per cent of carers report that caring has damaged their health (General Household Survey, 2000).
- 20 per cent have given up work to care (Carers UK, 2010).
- Over 70 per cent are worse off financially as a result of caring (Carers UK, 2010).
- Carers Allowance is currently the lowest income replacement benefit (Carers UK, 2010).

The National Carers Strategy (DH, 2008) has recently raised the profile of carers and outlined new strategies to support them. It addresses an over-reliance on family carers, which has not been balanced by sufficient or sustained support. The most recent carers legislation, the Carers (Equal Opportunities) Act 2004, places a duty on local authorities to identify carers and inform them of their right to an assessment, yet carers are rarely the focus of assessment and support (CSCI, 2009, p. 40). Research has highlighted the emotional, physical, social and financial costs of informal care and its heavy reliance upon women (Hirst, 2004; Carers UK, 2009).

Black and minority ethnic carers: invisible in social policy?

The experience of black and minority ethnic carers tends to be affected by the marginalisation of 'race' equality within social policy, which results in the specific circumstances and needs of black and minority ethnic communities remaining invisible and excluded from mainstream service delivery (NBCCWN, 2008a, p. 10). The first National Carers Strategy *Caring about Carers* (DH, 1999) contained little direct reference to black and minority ethnic carers, with correspondingly poor outcomes for these communities (Hepworth, 2001). Similarly, the updated strategy *Carers at the Heart of 21st Century Families and Communities: A caring system on your side, a life of your own* (DH, 2008) has not provided the necessary guidance or recommended the appropriate pilots to ensure that services are delivered in ways that are accessible and sensitive to the specific needs of carers from black and minority ethnic backgrounds (NBCCWN, 2008a, p. 1; 2008b).

The lack of central direction places greater onus on involving black and minority ethnic organisations and carers in the implementation of the Carers Strategy at a local level. However, many Primary Care Trusts and

local authorities have little knowledge of their community groups and no meaningful engagement with those living with disabilities (Roulstone and Hudson, 2007; Stuart, 2008).

Structural disadvantage

- Black and minority ethnic communities experience poorer health than the White British population (POST, 2007).
- Households tend to be younger and have lower income, but provide at least as much care as White British households (ONS, 2001).
- Pakistani and Bangladeshi women are providing significantly more care than other ethnic groups (ONS, 2001) and are more likely to be represented in the bottom tertile of household income (Nazroo, 2006).

With regard to structural disadvantage, research confirms that black and minority ethnic communities are more likely to reside in deprived areas, experience poverty, live in overcrowded and unsuitable accommodation, be unemployed and suffer ill health (Nazroo, 2006). Having a substantial caring role also increases the likelihood of poor health and socio-economic deprivation (Carers UK, 2009), yet at the same time black and minority ethnic carers' access to support is often considerably restricted (Williams and Johnson, 2010).

Resources 1

The National Black Carers and Carers Workers Network (NBCCWN) is hosted by the Afiya Trust and works with a range of partners, including the Department of Health, the Association of Directors of Adult Social Services, Carers UK,[1] The Princess Royal Trust for Carers[2] and Crossroads Care,[3] to tackle inequalities in health and social care and to ensure that the needs of carers from black and minority ethnic communities are addressed in policy, practice and service provision. The NBCCWN operates as a resource for agencies in the voluntary and statutory sectors and assists them to identify and respond to the specific needs of carers. The Network's research report and practice guide *Beyond We Care Too* **(NBCCWN, 2008a)** is available from **www.afiyatrust.org.uk**.

[1]**Carers UK** is a national membership organisation of carers that campaigns for change with and on behalf of carers. It assists health and social care professionals to develop services and support through research, consultancy, information and training. **www.carersuk.org**

[2]**The Princess Royal Trust for Carers** is the largest provider of comprehensive support for carers and young carers in the UK and has an extensive network of independently managed carers' centres. It also conducts research and campaigns for change. **www.carers.org**

[3]**Crossroads Care** is a national organisation that supports carers by giving them a break from their caring responsibilities. **www.crossroads.org.uk**

The Carers Strategy (DH, 2008) sets out to achieve the following core aims over the next decade so that carers will:
- be treated with dignity and respect as expert care partners;
- have access to the services they need to support them in their caring role;
- be able to have a life of their own;
- not be forced into financial hardship by their caring role;
- be supported to stay mentally and physically well.
In addition, children and young people will be protected from inappropriate caring roles.

A **Standing Commission on Carers** was appointed in 2007 to oversee the implementation of the Carers Strategy. The Commission has a strategic role in advocating for carers both within government and with external stakeholders. **www.dh.gov.uk**

Black and minority ethnic carers: not 'hard to reach' but 'easy to overlook'

2

Although health and social care organisations have a responsibility to ensure equality of access and service uptake (Race Relations Amendment Act 2000; Equality Act 2010), research suggests that few statutory and mainstream voluntary organisations successfully promote diversity (Butt, 2006). This section outlines some of the barriers that black and minority ethnic carers encounter, together with good practice responses to these issues (Resources 2).

> *'I'm a wife, mother, nurse, teacher, administrator, cook, cleaner, decorator, a great inventor and counsellor … As my daughter's needs grew, I tried to keep up without realising the unrealistic demands I placed on my mind, body and soul. It took a team of workers round the clock to fulfil all the roles. Then I understood what a "carer" is.'*
> (Asian mother of a disabled young person, quoted in NBCCWN, 2008a, p. 52)

Recognition of carers and acknowledgement of their rights are relatively recent developments in social policy (DH, 2008). Traditionally, caring has been located within a woman's family role and family members from all communities frequently have difficulty identifying with the social and political concept of 'carer' (NBCCWN, 2008a).

The experience of black and minority ethnic carers tends to be compounded by obstacles to service access, such as language barriers, unrepresentative staff, complex service structures and lack of information about rights, entitlements and available support (Mencap, 2006). Significant numbers of black and minority ethnic elders are unable to speak English and may not read or write in their own language. These carers are likely to value 'face-to-face' contact and first language support (Resources 2).

Sensitive outreach and proactive identification of carers have proved to be important prerequisites to effective assessment and support (Resources 2). However, mainstream organisations are often unwilling to commit the necessary time and resources and defend their lack of engagement by labelling black and minority ethnic carers 'hard to reach' (NBCCWN, 2008a). Similarly, the assumption that these carers 'look after their own' continues to be used as a justification for lack of support and low take-up of services (Mir, 2007; CQC, 2010, p. 41).

Research also describes an approach to assessment and service delivery that is insensitive to specific needs associated with culture, language, religion, gender and diet (Mencap, 2006). Mainstream organisations should identify and consult with local black and minority ethnic carers and groups so that they are involved and not marginalised in the planning and delivery of services (Resources 2).

Resources 2

Dudley Metropolitan Borough Council has extended its outreach to minority ethnic groups within the area and has a specific post dedicated to developing services for people with learning disabilities and their families. The post holder has been working with Pakistani carers (**Ehsas Carers**) to enable them to access mainstream services, raise funds and take group action. This has helped to reduce the stigma associated with learning disabilities and has promoted community ownership of the issues. The group assists public agencies to provide accessible information and culturally appropriate services. **Phone: 01384 422522; www.barnardos.org.uk/fitbc.htm**

The Princess Royal Trust Coventry Carers Centre is a mainstream voluntary organisation, which has attracted large numbers of black and minority ethnic carers, including over 600 young carers, through culturally appropriate outreach, consultation and support. The centre includes carers from black and minority ethnic communities as trustees and has

facilitated their involvement in the training of health and social care professionals. **Email: umasharma@coventrycarers.org.uk**

Hertfordshire County Council (Adult Care Services) produced the **'Getting in Touch' DVD** after community groups raised concerns about statutory providers' reliance on translated materials as the only alternative for promoting services. 'Getting in Touch' is a multilingual DVD showing carers how the council can support them in their caring role. **www.hertsdirect.org/carers**

Tameside Adult Services have pioneered a multilingual Co-worker Scheme, where co-workers act as outreach staff to assist those with caring responsibilities to contact services. Co-workers provide language and cultural support during assessments, play an important role in identifying unmet need and assist services to respond appropriately. **www.tameside.gov.uk/socialcare/raceequality/coworkerscheme#4**

3 **Mainstream or separate black and minority ethnic services?**

The low take-up and Eurocentric nature of mainstream services has raised ideological and policy issues about whether appropriate provision should be through mainstream or separate black and minority ethnic services (Chouhan and Lusane, 2004). More recently, the shift in focus from 'race' equality to a single equalities agenda (Resources 3) has created uncertainty about future funding for black and minority ethnic voluntary sector groups and could threaten their sustainability (NCVO, 2010).

In order to address racism, policy, legislation and service provision should confirm that black and minority ethnic carers are within mainstream society. However, the principle of mainstreaming is frequently synonymous with a generalist approach, which disregards the needs of these communities (Hepworth, 2001).

Research suggests that mainstream organisations are often lured by funding to address black and minority ethnic carers' needs, but lack the commitment and strategic planning to integrate this provision into mainstream services (NBCCWN, 2008a). Those who are employed by mainstream organisations to work exclusively with these communities, frequently encounter isolation and lack of support in time-limited, under-funded projects (Mir, 2007).

Carers have highlighted the advantages of the black and minority ethnic voluntary sector, such as accessibility, cultural and linguistic relevance, expertise and proactive awareness of need. Community groups provide a locus of cultural identity and cohesion and play an important role in mediating between carers and mainstream institutions (Chouhan and Lusane, 2004; NBCCWN, 2008a). Chouhan and Lusane (2004) suggest that with appropriate development and investment, these organisations are the best means of promoting the social inclusion and civic engagement of black and minority ethnic communities.

While racism increases the need for this sector, it also compounds its difficulties so that many organisations lack the infrastructure and funding to succeed. Since two-thirds of the funding comes from central or local government, changing political environments and initiatives are a risk factor for survival (Reid, 2004). The prevalence of short-term funding reflects tokenism and a lack of commitment to long-term service provision. Typically, this sector has been marginalised in partnerships, policy consultation and decision making (NBCCWN, 2008a).

The change of policy focus from the Labour Government to the Coalition Government's vision of a 'Big Society' holds opportunities and threats for this sector. Black and minority ethnic communities are accustomed to operating a version of this voluntary and community-based model because of their exclusion from or neglect by statutory agencies. However, it will be important to ensure that black and minority ethnic-specific needs are not ignored in the planning of the new structures and strategy.

The National Black Carers and Carers Workers Network (NBCCWN) has called for policy makers and service commissioners to utilise its experience and grass-roots knowledge so that the needs and circumstances of black and minority ethnic carers are made visible in policy, practice and service provision. Since black and minority ethnic organisations have a central role in supporting carers from these communities, the NBCCWN (2008a) recommends that they should be adequately resourced and involved in the design and delivery of services. At the same time, mainstream agencies must ensure that they are promoting equality and addressing the specific needs of carers appropriately (Resources 3).

Resources 3

The Equality Act 2010

The Equality Act aims to simplify and extend previous equalities legislation by establishing a single Equality Duty covering eight protected characteristics: 'race', disability, gender, sexual orientation, age, religion or belief, pregnancy and maternity, and gender reassignment. While there has been widespread concern that a single Equality Duty will detract from the significance of 'race' equality issues and diminish agencies' duties on these grounds (ROTA, 2008), the new legislation requires public bodies to consider how their policies, programmes and services affect disadvantaged groups within the community. The black and minority ethnic voluntary sector is well placed to offer specific examples of discriminatory outcomes for carers and to lobby on this duty. At the same time, practitioners and mainstream organisations can use this duty as a lever for consulting with black and minority ethnic voluntary agencies and carers and for involving them in setting equality objectives, developing action plans and reviewing progress.

Following on from the Coleman ruling, *Coleman v Attridge Law [2008] IRLR 722*, the Equality Act introduces new rights for carers on the grounds of their caring role, including protection from discrimination in the workplace and in the provision of goods and services. It requires public bodies to address inequality on the grounds of socio-economic disadvantage and is significant in terms of recognising that discrimination can occur on various grounds simultaneously. This provides an opportunity to address support needs arising from two or more protected characteristics; for example, lesbian carers from black and minority ethnic communities. **www.equalities.gov.uk**

4   **Service user and carer involvement in health and social care**

The involvement of service users and carers in the planning and management of public services has become a key concept in health and social care, with an increasing requirement for this in legislation and policy (DH, 2007a; EHRC, 2009). The principle of participation has gained influence in related areas, such as the training and education of professionals, occupational and professional practice and user-controlled services and support (Nolan *et al.*, 2007). Similarly, the involvement of users and carers is seen by many as central to achieving the objectives of the personalisation agenda, which aims to increase independence, choice and control through the introduction of self-directed support and Individual Budgets (DH, 2007b; Glynn *et al.*, 2008).

The participation of black and minority ethnic carers has the potential to reduce health and social care inequalities, improve services and inform professional practice (Beresford, 2007; Stuart, 2008). However, studies indicate that black and minority ethnic communities and carers are under-represented in mainstream involvement initiatives, as well as in service user movements and user organisations (Carr, 2004; Kalathil; 2009). Beresford (2007) cautions that unless specific provision is made to engage marginalised groups, user and carer involvement will continue to reflect broader social divisions and exclusions (Resources 4).

The new direction in social care

To date, the take-up of Direct Payments by both carers and people from black and minority ethnic communities has been low (Glendinning *et al.*, 2009). Pilot projects suggest that Individual Budgets have the potential to deliver the core outcomes of the National Carers Strategy (DH, 2008), but highlight the tension between a user-focused personalisation agenda and the recognition of carers' independent rights and support needs (Glendinning *et al.*, 2009). While Direct Payments and Individual Budgets have the potential to resolve the problems caused by standardised provision, carers could be left with the responsibility for managing them. This has implications for black and minority ethnic carers, who may encounter significant difficulties unless appropriate support is available (NBCCWN, 2008a) (Resources 4). In addition, the notion of independence may be interpreted differently by black and minority ethnic groups, who may prefer a community-based approach and a more traditional service.

The new direction in social care comes at a time when local authorities are struggling to fund all but the most vital services. Raised thresholds and funding cuts have consequences for carers left to fill gaps and for groups less able to access services (CQC, 2010, p. 15). There is a risk that a diversion of funding may result in the decommissioning of effective black and minority ethnic voluntary sector services that have taken years to establish (NBCCWN, 2008a).

Resources 4

Carer involvement

The National Black Carers and Carers Workers Network (NBCCWN) is currently promoting carer involvement in health and social care through a **National Black and Minority Ethnic Carers Panel**. The aim is to support and train carers to work strategically at local, regional and national levels. The Panel has had a prominent role in eight NBCCWN conferences since March 2008. This has acted as a springboard for further involvement activity, such as with the Standing Commission on Carers, the Care Quality Commission Carers Advisory Panel and the National Mental Health Development Unit. **www.afiyatrust.org.uk**

Direct Payments

Tameside Metropolitan Borough Council has achieved a high uptake of Direct Payments (DPs) among black and minority ethnic communities by means of targeted outreach by a specialist DP worker. This has included first language support and assistance with the process of receiving and managing DPs. Black and minority ethnic communities comprise 5.2 per cent of the population in Tameside, but account for 20 per cent of DPs. **www.tameside.gov.uk**

The BME Self Directed Care Project aims to increase the take-up of self-directed support among black and minority ethnic service users and carers across West London by facilitating access to culturally appropriate brokerage services, care planning and support. **www.selfdirectedcare-taha.org.uk**

Not a homogeneous group

5

Contrary to stereotypes, black and minority ethnic carers are not a homogeneous group. This section illustrates some of the complexity of working with carers and those they support, and considers the experience of four groups of carers, who are likely to have particular difficulty accessing services. Relevant links are provided where possible (Resources 5).

New communities

While there is a growing body of evidence relating to the needs of the more settled communities, little is known about the health and social care needs of those who have arrived more recently. Few local authorities have independent sources of information regarding the ethnic or cultural profile and changing circumstances of their local populations (Johnson, 2006). Carers from refugee and new migrant communities are likely to have difficulty understanding health and social care systems and to lack social networks. Access to support and services may be further complicated by language barriers and lesser rights for non-citizen members of black and minority ethnic communities. This highlights the need for further research and for outreach work with appropriate funding to sustain it (NBCCWN, 2008a).

Lesbian, gay, bisexual and trans (LGBT) carers

Black and minority ethnic LGBT carers are likely to be affected by the prevalence of both racism and heterosexism in health and social care and the assumption that LGBT identity is predominantly a White British, middle-class issue (Fish, 2006). Carers may lack community support because of the taboo around LGBT orientation and there are likely to be few, if any, mainstream projects that address the specific needs and circumstances of LGBT carers from black and minority ethnic backgrounds (Resources 3). Research suggests that black and minority ethnic LGBT people are disproportionately affected by homophobic violence, abuse and harassment and the costs of disclosure are likely to be higher than for their White British counterparts. These carers may not identify with the terms 'gay' or 'lesbian' (Fish, 2007) (Resources 5).

Carers with a learning disability

Research suggests that an increasing number of people with learning disabilities are taking on a caring role (Mencap, 2010). A large proportion are living with older parents and providing mutual care, while the move towards independent living implies that others may be supporting a partner. Black and minority ethnic people in this position may be unaware of their caring role, while professionals often fail to identify those with a learning disability as carers (Mencap, 2010). These carers may not have English as a first language and are likely to require information and assessments in appropriate formats, together with assistance to identify and access culturally sensitive support.

Transient communities

Gypsies and Travellers experience significantly poorer health than the general population, along with greatly restricted access to health and social care services. Sensitive outreach, by health visitors for example, can be effective in identifying and supporting women and young carers, who are likely to see caring as part of their family role (Matthews, 2008).

Conclusion

Despite greater recognition of carers, the specific needs and circumstances of black and minority ethnic communities continue to lack visibility in social policy and mainstream service provision. While the low take-up of mainstream services contrasts with the high take-up of black and minority ethnic voluntary sector services, this sector operates at the periphery and lacks sustainable funding and strategic representation. In a similar way, black and minority ethnic carers are under-represented in mainstream involvement initiatives and miss out on the opportunity to influence policy development. With appropriate infrastructure support, the black and minority ethnic voluntary sector could have a strategic role in promoting participation and ensuring that the inequalities experienced by carers in health and social care are addressed and not reproduced in current policy developments. At the same time, support for black and minority ethnic carers must be a mainstream issue.

Resources 5

Young carers

Barnardo's Carefree is a mainstream voluntary organisation, providing support and services to young carers in Leicester City and Leicestershire. Its **ASRNA Project** recognises that asylum seeker, refugee and newly arrived young carers are likely to experience additional challenges and disadvantages. The project provides support and advocacy in areas such as health, education and social inclusion. **Email: carefree@barnardos.org.uk**

Lesbian, gay, bisexual and trans carers

The Department of Health has published a series of briefing papers that address the health and social care needs of LGBT people, including: **Briefing 12:** *Lesbian, Gay and Bisexual (LGB) People from Black and Minority Ethnic Communities*, **www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance/ DH_078347**

Age UK's (previously Age Concern and Help the Aged) **Opening Doors** programme addresses the needs of older LGBT people, service users and carers. **www.ageuk.org.uk/health-wellbeing/ relationships-and-family/older-lesbian-gay-and- bisexual.** The programme includes a number of Age UK local projects, such as **Camden Opening Doors Project** in Central London.
Email: s.halls@ageconcerncamden.org.uk

Carers with a learning disability

The National Learning Disability and Ethnicity Network
www.lden.org.uk/index.html
Email: pam.smith@arcuk.org.uk

Foundation for People with Learning Disabilities
www.learningdisabilities.org.uk/our-work/family- support/mutual-caring

Transient communities

The **Friends, Families and Travellers** project supports Gypsy and Traveller communities in a range of ways, including access to health and social care services. Almost half of the staff team are Travellers. **www.gypsy-traveller.org**

Northampton Travellers Action Group (NTAG) is a consultative group of Travellers and Romany Gypsies. **www.northamptonboroughcouncil.com**

The **Countywide Traveller Unit** in Northampton works with a specialist health visitor to provide holistic support to Travellers. The service works with the voluntary and statutory sectors and provides cultural information, training and advice to professional groups. **Email: swilkinson@northampton.gov.uk**

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We welcome feedback on this paper and on all aspects of our work. Please email *briefings@racefound.org.uk*

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