Support for Black, Asian and Minority Ethnic carers
A GOOD PRACTICE BRIEFING

Summary

People from Black Asian and Minority Ethnic [BAME] communities make up over 30% of London’s carers.¹ Research shows that the BAME carers are more likely to experience poor health and in the future - increased caring responsibilities. These statistics highlight a need for increased services and support for BAME communities, a challenge which local authorities and other local organisations must respond to if they are to meet the needs of their local communities. This briefing is the outcome of a wide consultation with BAME carers and carers’ workers and identifies the key features of a good service and highlights some examples from practice, showing how the barriers can be overcome.

What are the issues for BAME Carers?

People from BAME communities make up over 30% of London’s carer population providing 20 hours a week or more care² and members of the Bangladeshi and Pakistani communities are more than twice as likely to become carers than the general population.³ It has been suggested that the 2001 Census “may significantly underestimate the number of people from black and minority ethnic groups, particularly in inner London.”⁴

The likelihood of caring and of ill health increases with both deprivation and with some ethnic origins. Research shows that some ethnic minority communities experience poorer health, lack access to some form of health provision, and have lower levels of satisfaction with health provision. The boroughs in which people are most likely to become carers are Barking and Dagenham, Newham and Tower Hamlets, where there are large ethnic minority populations. These areas have also rated highly in analyses of deprivation and poor health.⁵ Carers from BAME communities are therefore multiply disadvantaged in their own health, the health of those they care for and problems in accessing health and social care services.

The fact that some minority populations such as asylum seekers can be more transient can lead to more ‘hidden carers’ who are never identified and never have access to the support and services to which they are entitled. Cultural assumptions are made which are often erroneous, for example that Asian elders will be looked after by their own families and communities as they

¹ Census 2001 Office for National Statistics
² Census 2001 Office for National Statistics
³ Census 2001 Office for National Statistics.
⁴ Laing, Trends in the London carers market – Kings Fund 2005
⁵ Who Cares? Geographic variation in unpaid caregiving in England and Wales: evidence from the 2001 Census – Office of national Statistics
become frail when in reality, evidence shows that this is increasingly not the case.⁶ BAME carers continue to be excluded by negative attitudes and poor quality services, which consistently fail to recognise cultural differences.

Carers London together with the London Black Carers Workers Network [LBCWN] consulted carers and carers support professionals about their experiences of services and what support made a difference to them⁷. This report reveals their assessment of services for carers in London and highlights examples of good practice currently carried out by LBCWN members.

What makes successful BAME carer support?

Carers were asked to come up with three basic ingredients which they felt were essential for carer support to be effective for BAME communities. Their responses can be broadly grouped into five areas:

- **Simple, clear and accessible information:**
  Some carers felt that they did not know where to start to begin seeking information about the support available to them. Several spoke of the need for information to be simple, clear and not confusing. Of those for whom English is not the first language, most felt that printed information in their community languages would be useful but 30% did not, indicating the need to find other ways to reach those for whom language is a barrier.

  "More information, accessible information is needed for carers."

  "Caring would be easier for me if I had information about who to contact in emergencies."

  "Councils could improve the lot of carers by giving information to let the carers know what they are entitled to and where and how to apply."

- **Financial constraints:**
  Many felt that insufficient resources were directed toward BAME carer support, so that there were often long waiting lists or what they needed did not exist at all. Many also felt that they would be better able to take advantages of what was available if they themselves were financially better off or if financial support were available.

  "They should put more money into BME groups."

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⁶ Naina Patel, Policy Research Institute on Ageing and Ethnicity 2005
⁷ In 2006 Carers London and the London Black Carers Workers Network (LBCWN) brought together more than 100 carers and carer support professionals from London’s BAME communities. Over 60% of the audience were carers who cared for people from right across the spectrum of physical disability, mental illness and old age. The carers themselves were aged between 37 and 78 and represented a variety of London’s BAME communities.
“I would benefit from more financial support, like free transport and reduction of council tax.”

- **BAME carer involvement in planning, monitoring and evaluation:**
  Carers felt it was essential that carers from BAME communities be effectively involved in the inception, planning and evaluation of services, including those for people with disabilities. Carers felt that simple consultation was not enough and were exasperated by the “tick box” approach so often adopted. For involvement to be effective and genuine in needed to be properly resourced and carers properly informed and trained where necessary.

  Under 25% of the carers felt that their local councils listened to them when planning services for carers and cared for. Only a third felt their local NHS did so. 60% felt that they did not know who to talk to in their local council and NHS to tell them what they need from services.

  “BME carers should be involved wherever possible.”

  “There needs to be resources to enable meaningful participation.”

  “Involvement of carers in decision making is needed.”

- **Sensitivity to cultural and individual requirements and ability to meet these needs:**
  Carers felt it was essential that services were sensitive to the whole range of cultural requirements which individuals from BAME communities might have. The ability to negotiate language barriers is essential; food must be appropriate; same sex care workers must be available where needed; and respite care must be able to accommodate all cultural and religious needs.

  Sensitivity to cultural differences is only a start, carers told us. Services must also be flexible enough to be able to genuinely meet the many and varied needs arising from cultural diversity. Better use needs to be made of direct payments, including better and more accessible direct payments support services, so that they are of genuine use to carers from BAME communities.

  A third of the carers questioned felt that language or cultural barriers had prevented them from accessing health, social care, information, benefits or leisure services in the preceding 12 months. For many language barriers still hinder access, whether through a lack of translated information or a shortage of interpreters; and shortage of or long waiting lists for culturally appropriate services remain.
“My local Trust do not have a clear strategy for carers. Carers get lost in the provision gap and are left unsupported for long periods of time.”

“There needs to be a real understanding of cultural differences and dynamics”.

“We need appropriate respite that it culturally suited to our needs.”

“The local care agency is not ready to listen to our cultural and religious needs and provide a suitable home care package to our requirements.”

“Access to direct payments would help facilitate my carers’ role.”

- Recognition and real commitment from service providers:
  Service providers cannot adequately support carers until they recognise carers contribution and fundamental role as providers of care, involve them in planning and delivery, and support their wider aspirations. Carers from BAME communities feel that they are all too often being addressed on a “tick box” basis without a genuine commitment to meet their needs. Carers want to be involved in decisions and receive recognition and respect for their role from key providers of care. Some carers also want to have the opportunity to be involved in the planning and delivery of services.

“Providers and commissioners must listen to carers and understand the multi-tasks carers provide on a 24 hour basis. This would give them a deeper understanding of carers’ needs for support.”

“Carers should be respected and heard. Agency staff should be trained properly and not try to dictate the care.”

“I wish they would listen to me and improve services, not use me as a tick box.”

“I need financial help toward the cost of training and equipment.”

- A life outside of caring
  Fewer than half those surveyed had ever had a carers assessment and less than a third had one in the preceding 12 months. 80% would like to have worked, but felt it was impossible because of inadequate alternative care facilities.
What's being done in London?

Progress is being made in some areas in addressing the needs of BAME carers by including them in planning and management of services. Examples of this included:

- A BME carers forum
- BME staff consultation group
- Training and regular support group meetings
- An advisory committee consisting of carers from BME communities

However, it wasn't all good news.

“They do not take any steps unfortunately, they block delivery.”

“What steps do they take? None.”

BAME Carers and the Law

Every UK citizen has the right not to be discriminated against on racial grounds.

- The Race Relations Act 1976 makes it unlawful to treat a person less favourably than others on grounds of race, colour, nationality or ethnic origin. This applies to people in employment, education, training, housing, and the provision of goods, facilities and services.

- Following the Inquiry into the murder of Stephen Lawrence, the Government passed the Race Relations (Amendment) Act 2000. This legislation places a ‘general duty’ on all public authorities to promote race equality and to make this aim explicit in their policies, practices and procedures. Public authorities - including social services departments, health agencies and housing departments - are expected to ensure that they promote racial equality in everything they do – for example, consult BAME carers’ representatives when making significant changes to carers’ services in their area, and monitor the impact of their policies on BAME communities.

- The Race Relations Act 1976 (Amendment) Regulations 2003 implemented the European Council Article 13 'Race Directive'. The regulations enhance the Race Relations Act by, for example, amending the definition of indirect discrimination and changing the way in which the burden of proof applies. They also a number of exceptions from the legislation.

Social Care Institute for Excellence www.scie.org.uk
Good Practice

There is genuinely good practice being achieved in London, which is meeting the needs of carers from BAME communities and helping make enormous improvements in the lives of those who access them. Two of the examples highlighted at the event were Mindcare, the Lambeth African Caribbean Carers Mental Health Therapy and Support Group; and the Black & Minority Ethnic Carers Support Service which provides several services across a number of boroughs in north east London.

Mindcare – Dianne King

The Mindcare project arose out of the negative impact which mental health problems had on the BME communities in Lambeth. Carers were excluded from services and their own distinct needs are often ignored.

Dianne King realised that African Caribbean carers with mental health problems in Lambeth were particularly marginalised. Through a program of “assertive outreach and radical networking” Dianne set out to reach carers, some known to the system and many not. Many of them “found the system lacking and riddled with historical issues of inequality and mistrust, which combined with cultural pride and a lack of awareness of how to navigate the system.”

Mindcare conducted a thorough consultation with African Caribbean carers and identified the following needs:
- Emotional Support and training in stress management techniques.
- Practical support and advice, including financial advice.
- Advocacy support.
- 24 hour access to professionals in emergencies and crises.
- Access to adequate respite care.
- Good quality information.

Mindcare aims to:
- Raise awareness of African Caribbean carers issues in Lambeth.
- Support carers individual health concerns in a safe, confidential, therapeutic environment.
- Bring carers together to reduce isolation and help carers recover from hurtful experiences.
- Provide carers with an opportunity for a break in an environment sensitive to the cultural needs of the family.

Carers themselves decide what the service offers. There are monthly discussion groups, relaxation and therapeutic activities, social events, access to training and other opportunities and an annual health retreat. Service changes are carer led and the subject of consultation. Carers are also involved in discussions around developments in mental health policy and other related issues and the feedback from these discussions goes to policy
makers and practitioners. Carer involvement is built into the service and there is a strategic commitment to an ongoing policy of involvement in all aspects of it’s work.

Black and Minority Ethnic Carer Support Service (BMECSS) – Faiza Rizvi

BMECSS is an innovative, independent, community based service which offers a number of projects in boroughs across north east London. BMECSS has achieve ISO 9001 quality standards and has Investors in People status and has carers on it’s management committee.

BMECCS aims to offer culturally appropriate, ethnically sensitive and fully accessible services to carers from all BAME communities in it’s catchment areas. The services and projects are:

- **Sitter Service**: Using trained and registered sitters from local BAME communities, the service provides culturally appropriate home based respite for carers in Enfield and Haringey.

- **BME Carer Support Group**: Offers mutual support, social events, trips, massage and other therapeutic activities. The group also acts as a first point of contact group, making referrals to social care providers.

- **Bereavement Support Project**: BMECSS is a partner in the project in Haringey, which aims to offer culturally appropriate support to families facing bereavement.

- **Haringey Carers Forum**: Advises Haringey Strategic Partnership on carers issues, informs development of new services and consults with carers.

- **North London Carers Learning Network**: Aims to promote learning to carers across North London offering a training needs assessment, support in developing training plans, providing training, and high quality alternative care while the carer undertakes training. BMECS also offers NVQ Care Level 2 to carers and those from BAME communities who work in the care industry.

- **Care Worker Project**: Provides free training on manual handling, health & safety, record keeping, personal hygiene to BAME unemployed people interested in care work.

- **Leadership Project**: In partnership with Birkbeck University BMECSS offers free leadership training to residents of certain ‘regeneration’ wards across 3 London boroughs. The training is aimed at enhancing understanding and involvement in local policy and decision making.
Professionals working with BAME carers - Hertfordshire

Having information translated is an important way of reaching BAME carers; access to carers workers who can put carers in touch with support groups, services and other professionals is also vital.

Hertfordshire County Council employs an Involvement Worker for Black and Minority Ethnic Users and Carers to ensure that the services meet the needs of carers. She works with carers professionals to increase their awareness of BME carers’ needs – Herefordshire have developed a specialist resource called ‘10 Key Words’ has been piloted so frontline staff can learn a few key words in Urdu, Punjabi and Gujarati, some of the most common minority languages in Hertfordshire.

This can be viewed on line at www.hertsdirect.org/carers under BME Carers; telephone 01707 280659 to receive a free copy.

More information/ signposting

Carers UK

Carers UK is the voice of carers. Carers UK fights to end the ill health, poverty and discrimination faced by carers as a direct consequence of caring. Carers UK improves carers’ lives by providing information and advice on carers' rights and campaigning for changes that make a real difference for carers. Carers London reflects the aims and values of Carers UK in the Capital.

Carers UK produces a leaflet called Balancing Life and Caring, which is translated into ten languages for BME communities. It covers the basics of work, leisure and learning opportunities as well as what is involved in a carer’s assessment and lists a series of useful contacts www.carersuk.org

London Black Carers Workers Network (LBCWN)

LBCWN was set up in 1994 as a network of carer support professionals from London’s BAME communities. The network is facilitated and administered by Carers London and seeks to offer networking, information and good practice exchange and mutual support opportunities. It also offers opportunities for issues of relevance to London’s BAME communities to be aired, gain a raised profile and feed into policy making forums. For more information contact Carers London, Carers UK, Ruth Pitter House, 20—25 Glasshouse Yard, London EC1A 4JT Telephone 020 7566 7847 www.carersuk.org

CARERS London Support for BAME carers
Carers UK Equal Partners helps carers to campaign and improve local services. We offer carers a programme of support including practical briefings and newsletters, training to help carers make their voice heard and the opportunity to share ideas and learning with carers groups across the UK. For FREE registration email equalpartners@carersuk.org or write to Carers UK Equal Partners, FREEPOST NWW8000A Manchester M4 9EZ [no stamp required]. www.carersuk.org/equalpartners