

**National Black Carers and
Carers Workers Network**



Beyond We Care Too

Putting Black Carers in the Picture

Bibliographic data in publishing

Published by Afiya Trust for the National Black Carers & Carers Workers Network

ISBN (10 digit): 0 9542288 4 7

ISBN (13 digit): 978-0-9542288-4-2

Beyond We Care Too 2008

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Acknowledgements

The **National Black Carers & Carers Workers Network** in partnership with the **Afiya Trust** would like to acknowledge the financial support of

- East Midlands Care Services Improvement Partnership (CSIP)
- The Department of Health
- Action for Carers and Employment (ACE National) led by CarersUK

This project followed the principles and practice set out in the NIMHE/CSIP Making a Real Difference Involvement Toolkit which can be used by any organisation to support and guide service user and carer involvement. The tools can be accessed through www.mard.csip.org.uk

The completion of this report was only possible thanks to the efforts of many individuals, organisations and carers. The editing and authorship was carried out by the **Steering Group**:

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Cally Ward, Valuing People Support Team, and **NAGLDE** (the National Advisory Group on Learning Disabilities and Ethnicity)

Foreword

I am delighted that the National Black Carers and Carers Workers Network has been able to maintain the initiative it began with Afiya Trust when it launched 'We Care Too' in 2002. Black and Minority Ethnic (BME) voluntary groups play a vital role because they provide most of the help that is needed by those within the BME communities who are acting as carers, often without knowing that they hold this honourable role title! We are all indebted to them. This study captures the important role BME carers provide, identifies how much remains to be done, and provides some encouragement and examples of good practice on which we can all build.

Surinder Sharma, National Director of Equality and Human Rights, DH.

We are pleased to include these further endorsements of the report:

I would like to thank the NBCCWN (National Black Carers and Carers Workers Network) for their hard work in bringing about this important piece of work. There is no doubt that we all need to work harder to ensure equality across the social care sector and this document helps us to focus on what needs to change to improve future practice. Beyond We Care Too should be welcomed by a wide range of organisations working with carers as a useful tool and SCIE will certainly be working to support the implementation of the key principles.

Julie Jones, Chief Executive, Social Care Institute for Excellence

The Afiya Trust and the National Black Carers and Carers Workers Network work in collaboration with partners to reduce the health inequalities of black and ethnic minority communities. By revealing the causes of disadvantage and isolation for carers within these communities, this research helps to identify potential solutions through its recommendations and PRIAE is pleased to be associated with its findings.

Policy Research Institute for Ageing and Ethnicity

How to read this report.

This report is meant to be of use to practitioners and policy makers, both in the 'mainstream' or 'generic' health and social care services, local and national government and third sector, and to those active in the BME communities themselves, either as workers and community representatives or as activists, to inform future developments. We have included some examples of 'practice ideas' (which may not quite qualify as 'good' or 'best' practice as they have not been fully evaluated), and the stories and words of carers from the communities. There is also a report on the analysis of data from our surveys of BME carers and care organisations delivering support to carers in BME communities, and a review of 'what is already known on this subject' from previous research. This does not pretend to be a fully academic report, but it has been compiled according to the standards expected of any such study. At the same time, it is unashamedly committed to bringing about change and improvement.

Following clarification of key terms and definitions, we have brought together some essential background to the project, and a brief review of previous research in the area along with such data as currently exists. We then summarise some of the key issues from the perspective of carers and carer support workers in the Black and Minority Ethnic communities, and report on the findings of our survey of carers and carer support agencies. Brief sections outline key issues from the perspective of different stakeholder groups, such as the carers of different 'diagnostic' or care-need groups (including 'young carers' and carers of older people), and we present a 'checklist' for those responsible for commissioning new services. Throughout all of this, the accent is on seeking to identify what are specific or different needs of relevance to BME communities, while acknowledging that carers in the BME communities also share in all the needs of the majority population.

Original data and supporting references

Readers of this report who wish to access the original data or any of the support materials and references cited, or to obtain a fuller bibliography of reports used in its preparation, should contact the Mary Seacole Research Centre, De Montfort University, Leicester LE2 1RQ (seacole@dmu.ac.uk). Access to the original data will be subject to approval by the National Black Carers & Carers Workers Network. It is likely that the final database (and numbers in any subsequent reports of the study) will be greater than that used for this report since responses have continued to be received. It is also hoped that future rounds of the survey and audit of good practice may be possible.

We Care Too

The original report remains an important document with key guidance and recommendations, which are still valid. It can be accessed via the Afiya Trust website: www.afiya-trust.org

Executive Summary

Introduction

Following the publication of the Good Practice Guide and report “We Care Too”, by the National Black Carers and Carer Workers Network and Afiya Trust, an audit of its impact was planned. As the announcement was made of a new National Carers Strategy, the opportunity was taken to develop this exercise into a review of the needs and experiences of Black and Minority Ethnic (BME) communities in Britain, in order to complement the formal consultation being undertaken by Government. This report presents the results of that survey and the experiences of carers (and carer support services) in relation to the needs of the BME communities.

Following a discussion of terms, including the application of the concept of ‘carer’ within the BME cultural communities, the report reviews the recent development of the policy and legislative context for caring. Not only does the concept translate poorly into minority languages, but policy development has largely been conducted in isolation from the specific needs of BME communities, despite some opportunities to highlight these ‘hidden carers. There were also (and may continue to be) taken-for-granted assumptions about the preferences of these communities. The new proposals can be shown to have considerable potential to improve the lot of carers in BME communities, if the opportunities are properly used and suitable resources provided.

A further section outlines the Race Equality agenda and duties under the emerging Equalities framework of legislation. This includes statutory duties as well as NHS goals set out in National Strategic Frameworks.

In the next section we bring together short essays from practitioners on the specific needs of a selection of care groups, identified by ‘condition’ or age and other factors such as particular forms of provision. These illustrate the ways in which ethnicity and racism may impact differently on carers and cared-for people within minority communities. Topics include Individual Budgets, people with Learning Disabilities, Young Carers, and people with Sensory Impairments (Hearing and Sight).

Existing research findings on BME carers and care needs are reviewed and the additional impact of caring (or of racism and social exclusion based on ethnicity) highlighted. Recent research documents the parlous state of carers in BME communities, especially when it is considered that these communities are on average younger – and poorer – than the majority population. The recommendations of these studies are presented.

We then present the findings of our own surveys of carers and carer support groups, and lay out the implications of these for policy and practice. We also describe the results of revisiting the examples of ‘Good Practice’ listed in the earlier We Care Too report. Several no longer exist and others have often struggled to survive or had to adapt, but a few have become ‘mainstreamed’ and are more securely delivering enhanced

services. Funding was the key issue in nearly all cases, along with the significant role of individuals as workers or as decision makers.

Across the voluntary sector, issues of funding were again reported as crucial, along with the need for a strategic and 'joined-up' approach. Information was needed by organisations as much as by individuals, and there was heavy reliance among the statutory sector and major voluntary sector groups on (often small and insecure) BME voluntary organisations to meet this, either in terms of needs assessment or training.

From the point of view of communities also, the role of the BME Voluntary sector was critical, although we noted considerable weaknesses in these organisations ability to provide full support to carers, and a need for training, information and support from 'mainstream' generic providers of carer support.

The report concludes with a selection of recommendations for those charged with commissioning health and social care as well as those providing it, and to the research sector, to improve the evidence available for planning.

Our findings may be summarised as follows:

Needs are universal; solutions may be different

People and carers from BME communities mostly have the same needs as others. However, culturally sensitive ways of enabling people to access services are needed, and some services may need to adapt the way they are provided to meet the needs of particular communities. Different communities are likely to require different approaches to meet the same needs.

Sustain and mainstream BME provision

Services for BME communities are often set up on a time-limited project basis, and are not always properly evaluated. As a result, they are vulnerable when project-funding ends. When planning a service development, it is important to consider how the service will be mainstreamed if it proves to be successful. It is also essential not to rely on the enthusiasm of one individual or just a few people. If the developments are justified, they need to be owned by the whole organisation.

Monitor, evaluate and collect data

It is important to know who is using the service, and whether strategies to increase accessibility or reach out to BME communities are effective. If improved health or well-being outcomes can be demonstrated, services will be more sustainable. If interventions are not effective then resources can be redirected.

Introduction:

The origins of this Study and its Predecessor: “We Care Too”

During and since the development of the first National Carers Strategy, the National Black Carers and Carers Workers Network (NBCCWN) have been engaging with the Department of Health (DH) to ensure that views of Carers from BME communities are heard and integrated. The national agenda, and in particular during the development of the first strategy, the DH, did not take into account the needs of Black carers. Whilst the DH was very keen to discuss the issue, and supported the production of the *We Care Too* guide, it did not give clear guidance to Local Authorities to ensure that the requirements or needs of diverse Carers were met. Therefore opportunities to ensure the National Strategy impacted well on BME communities were lost. Very little research on the needs of BME Carers has been completed, and most of that has been in consultation with the small pool of knowledgeable carers.

With limited support from DH in 2002 the National Black Carers Network (as it was then known), in partnership with the Afiya Trust, published a major good practice guide for supporting Black carers entitled '*We Care Too*'. This guide was actively promoted and championed across all local authorities by Andrew Cozens, Director of Social Services at Leicester City Council who was also the “Carers Lead” for the Association of Directors of Social Services (ADSS). In 2006, Afiya Trust was considering an update of the 'Good Practice Guide', but the project Steering Group considered that it would be more valuable first to undertake an audit of the impact of the original document, and began a survey of organisations and carers to explore the development of services for carers from Black and Minority ethnic communities.

As the recent consultation exercise around the 2007 Review of the National Carers Strategy and the New Deal began, there was a concern raised by the NBCCWN that the views of BME carers would again be omitted. The main reasons for this were:

- A lack of expertise in consulting and engaging BME carers
- A lack of contact and direct work, and membership by most mainstream carer organisations and
- A lack of awareness in the mainstream organisations of the actual needs of people who happen to be 'carers' from BME communities.
- The method being proposed to consult carers – an internet based system, would also not reach the 'hardest to reach' carers.
- During the process of the consultation some of the consultation events being held around the country were also held on the major religious days of the major faith calendars, one on Diwali and another on Eid.

As the NBCCWN was already engaged in a national consultation with BME carers through a project group evaluating the impact of the '*We Care Too*' good practice guide when the New Deal consultation and revision of the National Carers Strategy was announced, we were able to offer support to

the DH. In very productive discussion with the DH, it was agreed that findings from our research would be incorporated into the Revised Carers Strategy. This information is crucial as the results of our analysis and consultation will boost the information obtained from the formal consultation, which did not reach the BME communities through its mechanisms.

How the NBCCWN operates

The NBCCWN pulls together Carers workers and organisations who have direct contact with a range of Carers from BME communities and are able to represent the views gathered in a strategic, coherent way. There are three regional networks (London, North West, and East Midlands) and an Executive group. Much support to raise funds and house staff comes from the host organisation, the Afiya Trust and without this partnership the Network would flounder.

One of the many tangible outcomes arising from the publication of *We Care Too*, was the funding (from DH) of two part time Regional Black Carer Development officer posts at the Afiya Trust. These workers were responsible for developing and supporting Regional Black Carers and Carer Workers Network Meetings. These regional workers and the organisations or people on their databases (approx 500) across the country have been crucial in contacting Carers to encourage people to complete questionnaire forms, in some cases, in their own languages. This has been labour intensive and a small incentive (made available from CSIP) was offered to organisations to help them support carers to complete forms.

The NBCCWN elected a new Chair, Lina Patel, in June 2007 and as part of her 'Induction' process there were opportunities to meet new people involved in the revision of the National Carers Strategy and in the field.

In the process, the Chair and Executive group have developed strategic relationships and become engaged with the agenda to the point where the Strategy has had major input from the NBCCWN. Representatives from the Network have been involved in the Task Forces set up to review the National Carers Strategy and the Standing Commission for Carers and are soon to be involved in the Commission for Social Care Inspection (CSCI) Improvement Board.

Definitions

Because people use many of the terms used in this report in different ways, we set out here the ways in which we are using some important words or phrases.

'Black' or Minority Ethnic – BME

There is often debate about the use of these terms. It is important to note that 'ethnic' or 'racial' origin is not the only way in which people are defined as a minority – and that there is a lot of diversity among the 'majority' white population in Britain. Many new migrants are now experiencing the same sorts of problems and discrimination as was met by earlier settlers from Asia, Africa and the Caribbean. Some people use

the abbreviation 'BAME' to make it clear that they refer to people of 'Black', 'Asian' and other 'Minority Ethnic' origins. The majority of people of Black and Asian origin in Britain were born here, and in some places no longer form a minority of the population, but still experience a lack of support to meet their specific cultural needs.

We have used the term 'Black' to refer to people of Asian, African, African-Caribbean, Chinese and Vietnamese descent. While all are culturally very diverse, they share a common experience of racism and discrimination. 'Black' populations are neither homogeneous nor static. Within each group there are many sub-groups. In addition, with time, the demography of Black populations changes; second and third generations were born in the UK and racial mixing is common in Britain. Recent arrivals are largely refugee communities. Each adds to the mix of cultural dynamics, and it is becoming clear that many 'new migrant communities' are following the same experiences as the earlier BME and 'new Commonwealth' migrants.

We acknowledge that the NHS, social care services and the not-for-profit sector use the term 'ethnic minorities' to describe Black communities. NBCCWN makes a conscious effort not to use this description, as this terminology is not one with which all Black carers identify. Indeed, few people would refer to the "ethnic majority"! Discussion continues over the use of terms, and we have used all of these as seemed suitable in context, or as used by those studies we have drawn from, while ensuring that when a specific community is referred to we use the most appropriate and precise description (e.g. Sikh Punjabi, Gujarati Hindu).

Census, survey and routine administrative data confirm that Black (BME) communities experience disproportionate disadvantage. They are more likely to live in deprived areas, experience poverty, live in overcrowded and unsuitable accommodation, be unemployed and suffer ill-health. Additionally they experience widespread racial harassment and racist crime. The notion of an inclusive society is one in which individuals and communities are given adequate resources to fully participate in society. Black communities are excluded from participating fully in many aspects of life. In addressing this issue, regard must be given to race, gender, and culture and the impact of institutional racism, as recognised by the Macpherson ("Stephen Lawrence") Inquiry.

What is a carer? Why is this term so confusing?

Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

Defining the term 'carer' has always been problematic. The term is widely misused and confused amongst practitioners, policy makers and carers themselves.

Firstly, many carers see their role as an ordinary part of family life and it is difficult to determine at what stage day to day help and support offered to relatives friends or neighbours makes someone 'a carer'. Cultural differences would also impact on this as different groups and individuals

may find different levels of caring acceptable as part of day to day family life. Secondly, the term 'carer' is used interchangeably to describe both carers and paid care workers. Other terms such as 'informal carer' and 'family carer' are frequently used for unpaid carers to differentiate them from paid carers. This confusion could be minimised by the use within the sector of the term 'support worker' to describe those who are paid to provide care.

The Carers (Recognition and Services) Act 1995, and subsequent carers legislation, makes the distinction between carers and care workers:

No request [for a carer's assessment] may be made by an individual who provides or will provide the care in question - (a) by virtue of a contract of employment or other contract with any person; or (b) as a volunteer for a voluntary organisation.

Whilst this addresses the issue of paid and unpaid care the confusion continues with the lack of a clear and consistent definition within legislation and policy of who exactly is a carer. Legislation has given the right to assessment to those carers who 'provide or intend to provide a substantial amount of care on a regular basis for the relevant person'. It is left to assessing authorities to make a decision about what constitutes 'substantial' and 'regular'; they must take the relevant guidance into consideration when doing so.

Policy guidance offers the following:

The process of assessing the impact of the caring role on the carer, and thus whether the care provided is regular and substantial, is based on a consideration of two dimensions:

- *key factors relevant to sustaining the chosen (sic) caring role,*
- *extent of the risk to the sustainability of that role.*

Thus it is the 'impact' of the care that is of importance. When assessing the impact a number of factors should be taken into consideration such as the carer's age and condition of health. The length of time spent caring can be a factor, for those caring for people with learning disabilities it can be a lifelong commitment. For those caring for people with mental health problems care may be needed on a sporadic basis.

Other legislation such as the Work and Families Act 2006, which gives carers the right to request flexible working, narrows the definition of a carer by restricting it to relatives and those living at the same address, failing to recognise that neighbours and friends may also provide care.

Individual budgets are set to increase the numbers of carers who are paid for their work and this will affect their entitlement to a carer's assessment and, no doubt, muddy the waters of paid and unpaid care even further.

Why is this term especially problematic for people from BME communities?

Through common understanding in their own languages people from different communities can relate to different words for the same object.

For example most communities use 'spoons' for eating and cooking. There is in most languages a word for spoon and correct translation will conjure up the image of the same thing; maybe different shapes or sizes or materials, but essentially the same thing. The concept of a spoon exists. However in Gujarati or Urdu there is no word for 'fork', as forks are not used for cooking or eating, but only in gardening! Equally, there are some words which exist in other languages but do not translate easily into English. The use of 'Family' to translate *Biradari* (Punjabi/Mirpuri) or *Kutumb/Parivar* (the word for family in Gujarati) really does not conjure up the same thing: the 'English' nuclear family of two adults and 2.4 children. The Asian conception is the extended family of all those people who are related to you. In cross-cultural translation, explanations are needed instead of simply 'changing words'.

Similarly, in other languages the concept of the duty to look after your family exists, as it does in English. However the concept of having 'social services' only exists where there is a 'welfare state' and formal planning of 'community care'. British communities are beginning to understand the concept of a 'family carer' as an attached concept based on an understanding of social care. Many people from other countries do not have experience of a welfare state and therefore, amongst a whole range of concepts, would not understand the concept of a 'carer'. In addition to this we have yet to find a word in Gujarati, Urdu, Punjabi, Bengali which translates to 'a carer'. If the word does not exist, the concept cannot exist either.

Many British young Asian people still state that looking after a family means they care - without understanding the distinction required to recognise the additional responsibilities and activities involved in looking after someone who is sick, disabled or needs additional help.

(Note: at the end of our publication, we quote an Asian carer's experience of coming to understand this term)

Refugee/ Asylum Seeker

These two terms are often used as if they were interchangeable. In fact, they have very different entitlements although they may share common needs.

Refugee: A refugee is a person forced to leave his or her country of origin or habitual residence in search of safety in another country. The 1951 UN Convention defines a refugee as a person who 'owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable, or owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.' The Border and Immigration Agency of the Home Office defines the term 'refugee' as including only people who have been recognised as such by the United Nations High Commissioner for Refugees (UNHCR), or who have been granted asylum by a signatory to the 1951

UN Refugee Convention. Many voluntary sector and health workers do not make these distinctions, but it is important to note that the precise definition affects the degree to which a person may be entitled to support as a carer.

Asylum seeker: An asylum seeker is a person who has requested asylum or refugee status and whose application has not yet been decided. While entitled to support through the Home Office's National Asylum Support Service, they have no general entitlement to normal social care services.

Methodology: How did we reach the carers in this survey?

People from Black and ethnic minority communities are often considered 'hard to reach' but this is not necessarily true. Accessing BME carers is not especially difficult; but is a matter of time and resources. It is not so much a case of 'hard to reach', and has been described as more like 'easy to ignore'.

This survey has been unusually successful in accessing a significant group of Asian carers and especially older carers from the South Asian communities for whom English may not be their first language. This has been achieved through the active involvement of a large number of voluntary agencies who work with black and ethnic minority communities. Some of these voluntary agencies were Carer Centres with knowledge and expertise in relation to this work but others were community organisations, offering a range of culturally relevant services targeted towards specific ethnic minority communities such as the African Caribbean, Asian or Chinese communities.

Initially, we sent out the questionnaires to a large list of community organisations held by the network, including freepost return envelopes. They were sent by email to members of the London LBCWN network and some individual carers, Carers Leads in London and the major Carers Centres in London, which also passed on information to their carers and organisations within their Boroughs. Members of the network steering group used their personal contacts and presence at carers group events to remind people to submit their responses. Further, we circulated information about the survey to members of electronic discussion networks for people concerned with minority ethnic health issues. A link was placed on the NHS electronic library "Specialist Library for Ethnicity & Health", and with the agreement of the Carers Reference Group of the Association of Directors of Adult Social Services, the survey was cascaded via local authority carer lead officers to local networks of voluntary organisations to be distributed to 'black' carers for completion. The survey was also circulated through Carers UK to local and regional members, supported by a letter from Imelda Redmond and questionnaires were also posted on the websites of Carers UK and Afiya Trust.

A number of local black/minority ethnic community led organisations then responded and offered to support their members in completing and returning the questionnaires. Reminders were sent round the networks, and

copies of the questionnaire have continued to be returned after the deadline. These will be added to the database and held for future analysis at the Mary Seacole Research Centre. The way that this group of carers was accessed will have a significant impact on the findings in this survey. The carers who have responded are essentially 'in contact' with services of some kind. Carers who were accessed through Carer Centres are far more likely to have been informed about developments such as the 'New Deal for Carers' or signposted towards carer specific services such as carer's assessments. These findings should be considered with this in mind.

Minority ethnic carers

There is a major lack of baseline data regarding the numbers, role and experiences of carers within black and minority ethnic communities, although a few recent reports have attempted to draw out some distinctions and impressions (see Bibliography). Most of these have been based on the analysis of national surveys such as the General Household survey. However, in most of these general-purpose household surveys, sample is not large enough for systematic investigation of issues of race or ethnicity although these factors mediate the carer's experience and needs as well as their relationship with services and service providers. Demographic factors, culturally-held beliefs and practices, a recent history of migration and settlement, and social, economic and material disadvantage shape the demand for and supply of unpaid care in minority ethnic groups. Survey evidence highlights the diversity of patterns of care-giving within and between minority ethnic groups and the white population (Hirst, 2000). Demographic trends in minority ethnic groups point to significant changes in family and household size and structures, and an imminent increase in the number of older people from the cohort who migrated to Britain in the late 1950s and 1960s; expectations about marriage and inter-generational responsibilities are also changing. Higher rates of long-term conditions and morbidity in some sections of the minority ethnic population are likely to shape both the prevalence and nature of care-giving, and the carer's response (Nazroo, 1997). For these reasons, much more needs to be known about health inequalities among minority ethnic carers to inform policy thinking and service development. Further discussion of Census and other data may be found later in this report.

A recent UK wide study of carers of people with mental health problems in BME communities concludes that given their practical 'hands on' experiences, these carers have insights which could enhance the quality and efficiency of service provision. Three overarching messages for professionals working in mental health services emerged:

- Listen without judgement
- Work together with families
- Treat everyone as an individual but as a whole person in a social environment

The Policy and Legislative Context Past and Present

Recognition of carers and the development of legislation

Caring has historically been a hidden problem bringing isolation, financial hardship and associated health problems to people, predominantly women, caring for dependent relatives. The plight of carers first caught the public attention in Britain in the mid 1960's when, following the death of her parents, the Reverend Mary Webster wrote a series of letters to national media and MPs about her own experience of caring. The response from people in the same position across the country was significant and resulted in the establishment of the National Council for the Single Woman and Her Dependants in 1965. Pressure from this organisation brought about a number of financial benefits including tax concessions and pension credits for those giving up work in order to care, followed by Attendance Allowance and Invalid Care Allowance (ICA) in the 1970's.

In 1981 the Association of Carers, a second carers' organisation, was established. Campaigning by this group led to the extension of payment of ICA from single women only to married and co-habiting women. Carers UK is the result of a merger of these two organisations in 1988 and a subsequent name change in 2001 and continues to campaign successfully for carers rights in the UK and across the EU.

Local authorities were first required to consider the ability of carers to continue caring in the Disabled Persons Act 1986 and the NHS and Community Care Act 1990 strengthened this by requiring carers' views to be taken into consideration during community care assessment and care planning.

The first piece of legislation specific to carers was the Carers (Recognition and Services) Act 1995 which gave carers the right to request an assessment but only at the time when the cared for person was being assessed. Many carers remained unaware of this as there was no duty placed upon the local authority to publicise this right for carers. The Act required assessment to focus on the carer's ability to provide care, with a view to providing support where necessary, to sustain the caring role. This was, however, viewed with scepticism by many carers as they saw the assessment as a 'test' of their ability to care, and as a result many were reluctant to request assessment. Under this Act the results of the carers assessment can be taken into consideration when deciding what services to provide for the cared for person. This Act applies to carers of all ages.

In response to further lobbying from carers groups the Department of Health published 'Caring about carers: A national strategy for carers' in 1999, setting out the vision for carers support and services for the future. The strategy brought with it the Carers Grant, the first ring-fenced funding to provide breaks for carers, and kick started local action to support carers.

"This work was to break the mould of traditional Government working by cutting across different Departments and produce one of the most important policy documents in the history of carers." (Carers UK (2002) 'The History of Carers UK and the Carers Movement')

The strategy was closely followed by the Carers and Disabled Children Act 2000 which emphasised further the need to maintain carers' health and wellbeing. Now carers had the right to an independent assessment and the provision of services for themselves and not just for the person they cared for, although local authorities were given the power to charge for these services. The Act gave rise to voucher schemes for short-breaks to increase flexibility and choice and gave carers, including 16 + 17 yr olds, a right to direct payments. The restriction of the 2000 Act to carers over 16 and those with parental responsibility for disabled children raised concerns regarding the recognition and assessment of young carers.

The right for carers to have the same life chances as others was recognised in the Carers (Equal Opportunities) Act 2004. The Act acknowledges that carers should not be socially excluded as a result of their caring role, by placing a duty on local authorities to ensure that carers are identified and informed of their rights, that their needs for education, training, employment and leisure are taken into consideration and that public bodies recognise and support carers.

The duty on local authorities to inform carers of their right to assessment emphasises the requirement to actively seek out 'hidden carers'. This is particularly important in ensuring that people from BME communities are not excluded. To the disappointment of carers groups the Act failed to place any duty on other public bodies to recognise and support carers but it did allow local authorities to request co-operation from such organisations in planning services for, and supporting carers. This could, for example, be a request to a health authority to prioritise a carer for an operation or a request to prioritise a carer on a housing waiting list. Other authorities must give 'due consideration' to such requests. This represents increasing acknowledgement that the responsibility for supporting carers should be agreed across organisational boundaries to ensure that carers are recognised and supported by the whole of society and not just by social services. Quite simply, carers are everybody's business!

Recognition of carers and their contribution to society continues in "Our Health, Our Care, Our Say", the New Deal for Carers and more recently a Standing Commission for Carers, demonstrating the government's commitment to supporting those who provide unpaid care to family, friends and neighbours. The New Deal includes plans for:

- a new Carers Strategy,
- a national carers' helpline,
- emergency short-breaks or home based care for carers in crisis
- an expert carers' programme (following the model of the expert patient programme).

The New Deal has been widely welcomed but there remains concern that existing legislation is still not being implemented. The CSCI report on the state of social care found that:

Carers' responsibilities are increased by the trend towards ever-tighter eligibility criteria for access to services. Support for unpaid carers remains one of the biggest public policy challenges of our time. Last year we stated clearly that the onus was on councils to address this. This year, we find that services for carers remain patchy and limited, and that in many areas carers still do not have the same opportunities as other people. Carers continue to tell us that they only receive support when they reach crisis point, when what they need most is flexible respite care and sustained support. (Commission for Social Care Inspection (2007) 'State of social care in England 2005-06')

In addition, BME carers have been given little attention within legislative and policy documents, with no explicit mention of these groups in any of the Carers Acts and only fleeting references within National Service Frameworks (NSFs). The NSF for long term conditions recommends the identification of more carers who need support acknowledging that BME carers report significant problems in accessing carers' services. The NSF for Mental Health acknowledges BME groups as being at higher risk of mental illness than the wider population. Contributory factors may include stress caused by moving or displacement and discrimination. It is vital, therefore, that the new Carer's Strategy addresses the needs of BME carers and gives rise to robust implementation plans.

The new direction for social care holds a heavy focus on prevention and presents a vision of increased choice and control for service users through individual budgets (IBs) and personalised services. This comes, however, at a time when local authorities are finding it increasingly difficult to fund all but the most vital services. There has been a significant increase, from 53% to 62% in 2006-7, in the number of councils that only offer services to those with 'substantial' or 'critical' needs. A survey by Community Care suggests that the number of authorities setting their criteria at this level is set to increase. Research by Carers UK found that "over 40 per cent of those caring full time and not in work say that they cannot return to employment because of the lack of services available". At the same time, nearly one in five Pakistani women aged 30-pension age, and one in ten British Pakistani or Bangladeshi men aged 16-29, are also carers, when these communities are among the most deprived in Britain!

This situation is utterly incongruous and has been highlighted in the CSCI State of Social Care in England (2006-7) report. The government has responded by announcing a national review of eligibility criteria. Raised thresholds and subsequent cuts in services to those needing care will have an inevitable impact on carers as they are forced to fill the gaps and prop up services. It follows that those who are less able to access services, such as those from BME groups, are likely to suffer the greatest hardship as a result.

Further concerns are being raised around individual budgets. Whilst they may offer unprecedented opportunities for service users in increasing choice and control, there are concerns that carers will be expected to manage care plans and budgets and arrange for alternative care provision, particularly where the service user is unable to do so. For many carers this would present a significant challenge. For BME carers there may be additional difficulties, for example with language or understanding how to access systems. Appropriate support must be provided for service users and carers in this regard whatever level of responsibility they wish to take in managing their own care and support.

Carers are poorly represented among recipients of Direct Payments as are people from BME groups, and whether carers will routinely receive Individual Budgets (IBs) in place of conventional support services for themselves remains to be seen. The new concordat 'Putting People First' commits to 'personalised budgets for everyone eligible for publicly funded adult social care support' except in emergency situations.

A study by the Social Policy Research Unit in York aims to assess the impact of IBs for carers including identification of patterns among particular groups of carers, this should include minority groups. The study is scheduled to report initial findings as part of the evaluation of the 13 pilot sites for IBs in April 2008 with a full report in October 2008 (see SPRU website, below).

The personalisation of services offers great hope to people from BME communities as the essence of personalisation is to tailor services to individual needs and preferences. If the new vision becomes a reality, the problems caused by standardised provision, unable to provide for people with different cultural needs, may be resolved. The mainstreaming of IBs may, however, raise concerns about the decommissioning of carer support services through reduced or discontinued grants to carers centres to facilitate the funding of carers IBs. Services that have taken a long time to establish and *are* meeting the needs of carers must be protected. An unpublished survey by the Princess Royal Trust for Carers, of voluntary sector Carers Centres in England makes for worrying reading in this regard. The evidence shows that 95% expected getting funding for carers' support to get harder next year and that at least one of their services would be at risk during this Comprehensive Spending Review period: 20% felt their entire service did not have secure funding for 2008-9.

Many carers centres have been able to offer open access services to carers, for example, emotional support over the phone or peer support through connecting with other carers in the community, which may now be threatened. Where services that support BME groups have been absent decommissioning is less likely to be an issue but, in such cases, additional money would be needed to provide IBs.

Social inclusion and citizenship are also high on the agenda. In order to address the needs of diverse communities the individuals from these communities need to be actively involved in service design and provision. Empowerment is key to this process and local authorities need to actively

mobilise communities and build local capacity. The government set out plans for increasing local capacity in Firm Foundations which defined capacity building as: *'activities, resources and support that strengthen the skills, abilities and confidence of people and community groups to take effective action and leading roles in the development of their communities.'* This is particularly important where minority communities are concerned as they will undoubtedly be better able to shape services in line with self defined needs. Building further on this policy initiative, 'Putting People First' sets out to ensure a collaborative approach to future public service provision that will be "co-produced, co-developed [and] co-evaluated". The new performance framework is intended to drive delivery, the new requirement for Joint Strategic Needs Assessment being the linchpin of the 'system-wide transformation'.

The burden of inspection for local authorities has been well documented as have concerns about the perverse incentives sometimes brought about by specific performance targets. The Local Government White Paper set out plans to reduce this burden by scrapping existing inspection mechanisms such as star ratings, children's joint area reviews and comprehensive performance assessments, the aim being to:

provide freedom and space for councils to respond with flexibility to local needs and demands. It radically reduces national targets, tailors others to local circumstances and introduces a lighter touch inspection system. This means a stronger role for councils to lead their communities, shape neighbourhoods and bring local public services together (Department for Communities and Local Government (2006) 'Strong and prosperous communities')

The Health and Social Care Bill 2007 covers four key policy areas, one of which will bring together the functions of the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission. The new body will be known as the Care Quality Commission. But from 2009, there will be a radical reduction in the number of performance indicators to 198, councils will be expected to meet all the targets and to identify a minimum of 35 of them for specific improvement focus. Only one of the 198 indicators mentions carers:

NI 135 Carers receiving needs assessment or review and a specific carer's service, or advice and information (Communities and Local Government (2007) The New Performance Framework for Local Authorities and Local Authority Partnerships: Single Set of National Indicators)

This is not necessarily worrying as this will feed into the proposed new Comprehensive Area Assessment, a single, overarching system of inspection for all council services. It is intended to take a more holistic view of the council's activities comprising an annual 'risk assessment' and an assessment of the council's 'direction of travel' and 'use of resources'. This assessment should encompass the needs of carers as 'core business' reiterating the important point that carers are everybody's business.

The Race Equality agenda; how services should respond

There are a number of influences or legislative and policy drivers that should now affect the consideration and action of all agencies in the welfare field, whether statutory or voluntary. All are equally expected to comply with the new Equalities Agenda, including statutory obligations under the Race Relations Amendment Act, the expectations of the inspecting bodies (such as the Audit Commission, Healthcare Commission, Commission for Social Care Inspection and Equalities and Human Rights Commission) and the broader European 'Amsterdam Treaty' (Article 13) anti-discrimination provisions. In general, all of these expect that agencies will monitor their use by people according to their membership of groups which might be associated with inequality or discrimination (notably religion and ethnicity), and conduct Equality Impact Assessments of their policies and practices.

The Race Relations (Amendment) Act 2000, places a general duty on public authorities to promote race equality. The aim is to help public authorities to provide fair and accessible services, and to improve equal opportunities in employment.

Health organisations and local authorities should produce and maintain a race equality scheme (RES) which addresses the duty to promote good race relations, and provide adequate resources to carry out all requirements.

Local government organisations should, for example, encourage dialogue between different racial groups on the adequacy of service provision and keep accurate records of the ethnic groups in the area and their needs. Health authorities should, for example, promote participation by people from all racial groups in decision-making about the ways in which health services are provided and promote partnership with voluntary and community organisations.

The Disability Discrimination Act 2005 places a duty on all public sector authorities to promote disability equality. The Disability Equality Duty which came into force in December 2006 requires all public bodies to actively look at ways of ensuring that disabled people are treated equally.

National Service Frameworks (NSFs)

Several of the National Service Frameworks are relevant. In particular, the NSF for older people and the NSF for diabetes. Both set a number of relevant standards, for example the NSF for older people states that staff should communicate "in ways which meet the needs of all users and carers, including those with sensory impairment, physical or mental frailty, or learning disability or those whose first or preferred language is not English.... Interpreting and translation services should be made available". It goes on to say that the NHS, with councils, "should ensure that older people have fair access to programmes of disease prevention and health promotion.... These should take account of the impact of cultural and religious beliefs and lifestyles" . Similar implications can be drawn from the NSFs for long-term conditions, and that for Diabetes,

which also specifically explains the significance of ethnicity in relation to this disease.

The statutory guidance, ***Social Care for Deafblind Children and Adults***, outlines the rights of deafblind people and the duties placed on local authorities, including:

- identifying deafblind people,
- the provision of trained people to make assessments,
- the provision of appropriate services and information in appropriate formats.

The guidance and its duties are mandatory. The Commission for Social Care Inspection (CSCI) reviews compliance with the guidance as part of its regular inspection process.

Equality Issues for different care groups

In this section we have brought together some of the key issues faced by people in the BME communities within specific care-groups, since these may not always be the same, and to highlight the specific needs of these groups. We are conscious that we have not covered all specific groups, whether in terms of age or diagnostic condition, but hope that these examples, which share many common themes, will serve to illustrate the complexity of working with carers and cared-for people within BME communities, and point to some of the community-specific as well as care-needs-specific issues that can arise.

For example, our survey revealed that carers who support older parents who do not speak the language or have different cultural traditions face additional barriers in accessing acceptable support for the person they care for. This means that often they end up relying inappropriately on other family members for help or have to give up work. Carers describe having to use their lunch breaks to take appropriate food into hospitals, or rush home every lunch-time to make meals. This puts additional and unacceptable burdens on BME carers which other carers do not have to face. On a basic level, we feel that hospitals and community care providers should be able to offer culturally appropriate food.

Direct payments and disabled people

Carers of disabled people exist in all communities, yet where there is a lack of promotion of the term "Carer" in localities, this can result in a lack of care related services to BME communities, especially in relation to accessing Direct Payments, Respite Care and other (generally successful) independent living opportunities. Where there is a strong support service to all disabled people with a commitment to enhancing/extending services to BME communities, there is a strong possibility of better access to services from Carers of those groups. However all service delivery parties need to consider the following.

The Capacity of Voluntary Support Services. There are a dwindling number of support agencies across the country despite Government recommendations of the need for user led organisations in each locality. Local authorities need to recognise the added value for money gained whilst supporting a user led group. For example, Disability Direct Derby is grant funded by Derby City Council to the tune of £59,000 per year. This, although not a huge amount, enables the organisation to employ management and fundraisers who bring in additional funding for services in the city to the value of £500k per year. However, funding disability groups is not the only answer to the problem. Support services need to recognise that the needs of carers are of equal importance to those of disabled people. Too many disability groups offer biased advice, particularly in terms of Direct Payments and ILF. This is in itself a barrier created by those who face barriers themselves. Furthermore, those groups who have managed to extend services to carers can indirectly limit services to carers from BME communities, often through ignorance, but more often through no internal investment on BME support and forward planning. Additionally, the wider BME voluntary sector are traditionally more involved in campaigning and or just fighting for their own existence and often fail to support disability and carer groups. Nevertheless, all not-for-profit groups whether disability related or not need to address services to disabled people, carers and BME groups in order to provide maximum support to those who really need it.

The Operation of Direct Payments/ILF/Individualised Budgets. These appear to be a great idea, but may not be easily managed by disabled people and carers including BME groups. Very few local authorities have staff available at the assessment process who have a good cultural understanding of BME issues as well as the ability to speak local community languages. This in itself creates the first barrier. Should an appointment for an assessment be made, the vast majority of disabled people and carers from BME groups will not have had any pre-assessment support. This should, for example, include keeping a diary of what they would like to do (both personal care and socially) and what they actually do for at least two weeks prior to the assessment.

For those with language or communication difficulties, it is often suggested that a family member be present to “support” the individual in getting any thoughts / opinions across. This is not necessarily the best option, as it may mean that the assessment focuses on the family needs rather than the individual. The use of an independent advocate is the best option. However, there are only a handful of trained advocates who are actually aware of community care issues.

The award of a Direct Payment, ILF or an Individualised Budget creates more complications. Too many carers end up actually managing the finance which defeats the object of the initial award in most cases. Carers are not often fully aware of the liability implications of any financial irregularities. Equally some carers are nominated in care plans and by the disabled person to manage the whole award. Without correct support given to carers, there is a strong possibility of irregularities in financial & staff management.

Carers from BME communities need additional support in terms of understanding the limitations of an award as well. Most disabled people from BME communities on Direct Payments are over the age of 60 and often struggle to speak and understand English. When confronted with issues such as Employers Liability Insurance, Payroll, Timesheets and Monitoring forms, it becomes apparent that support services need to invest in additional support such as Independent Living Advisors who are able to speak preferred languages.

Respite Care: Very few people from BME communities actually request respite. Not because it is not needed, but simply because they don't know it is available. Those who do, often state that any respite offered was not culturally appropriate.

'My caring responsibilities change very quickly. My wife feels vulnerable and will not accept any non Asian sitters because she is unable to express her needs to other due to lack of communication in the English language'

Carers Networks: There are Carers Networks across the country who are either self-help groups or offer short-term day respite. However, again not many fully understand and / or address the needs of carers from BME communities. If you ask such carers, they are more than likely unaware of the groups who *may* offer some crucial support and thus go without.

Caring for people with Learning Disabilities

People from minority ethnic groups need to be included in *all* work to improve the lives of people with learning disabilities and their families. In 2001, the White Paper *Valuing People* said that the services and support for minority ethnic communities was not good. Alongside the White Paper the government published a report 'Learning disabilities and Ethnicity' by Ghazala Mir that gave a number of suggestions for improvements.

Two surveys of local Partnership Learning Disability Boards were commissioned by the *Valuing People Support Team* and while only half the Boards responded, the results showed that not enough progress had been made to improve the situation for people and their families from different minority ethnic communities. A few were beginning to develop better practice. However, only 22% of the Learning Disability Partnership Boards had undertaken an Equality Impact Assessment under the Race Relations Amendment Act, although 13% had taken one as part of a bigger Equality Impact assessment and 17% said they were planning to in the future. Half of all Partnerships Boards showed no action on undertaking Equality Impact Assessments.

Local agencies will need to have information on the communities they service and this will need to include involving people in discussions about *how* different communities perceive and relate to public services. Local agencies need to develop services that people from minority ethnic communities want to use. Family Carers, regardless of where they live,

how much money they have or their ethnic and cultural back ground have the right to expect that local services will provide them with the support they need to live a decent life and manage their all caring responsibilities. To do this local public services need to be able to identify and know who the family carers are in their area; provide them with the right information in the right format for them; and offer them an assessment of their needs. The challenge of the coming decade is to ensure that public services rise to the policy commitment of meeting the needs of all family carers within the diverse communities we live in.

Each time my son has thrown tantrums and I have tried to cope even though he has been physically abusive, I have tried to cope with his anger. On few occasions I have tried to link in with my GP. His response has been, "I cant' do much. I can make referral for residential care". He is fully aware that there are not many services that could meet his cultural and dietary needs. Sending my son to the residential care home means causing further problems to myself as he becomes more agitated and restless. It takes him several days to settle back home. Due to the stress of caring both my husband and I have developed our own health problems.

What saddens me the most that Asian and black people with learning disabilities don't seem to access the services they require. (Asian Carer of child with Learning Disabilities)

There are now well developed networks of people or agencies with increasing experience of providing services to people from BME communities with learning difficulties, including the 'Ethnicity Training Network'. A consensus view across this field, incorporating the views of BME people with learning difficulties and their carers, produced the following list of needs and recommendations.

- There should be more specialist BME workers, especially people with language abilities to communicate in the 'home language' of carers and cared-for people.
- It is important to build trust and cultural understanding – voluntary organisations play a crucial role in this as bridges between statutory bodies and individuals, but need to develop their capacity in dealing with both ends of this bridge.
- Users would like to see more one to one support for the cared for person, so the carer gets respite. This must come from a recognised person who can demonstrate the above cultural sensitivity and understanding of culture and/or language
- Similar sensitivity and familiarity needs to be found in "Sitting services" (providing company) – as family members such as "mothers in law" may have concerns about the provision of personal care.
- Carers want an opportunity to find an outlet from home as they will become stressed otherwise, and may need to be able to take part in cherished community cultural activities and obligations (which might include visiting relatives abroad).
- Support is needed for people to use the Race Equality Duty placed on statutory bodies, to get appropriate services.

- One off carer payments are liked but not always well understood.
- There are very strong family pressures to “look after our own” – especially in some communities, the daughter-in-law may be expected to care without outside help. Help will be needed to overcome or manage these expectations.
- Supporters and agencies need to “Listen without judgement”, especially when there are differences over cultural expectations and interpretation.
- Cultural assessment means not separating the person into parts or treating them mechanistically without reference to their family, cultural community and religion as well as a person
- It is also important to listen to and respect people with learning disabilities as carers, in the BME communities as in the majority population.
- BME people with learning difficulties and their carers also want to say “Nothing About Us Without Us”.

Young Carers

The legal definition of a young carer is stated in the Carers’ (Recognition and Services) Act 1995:

“Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis.”

However, it is important to take into account not only the extent and nature of caring but also the actual or potential impact it has on the young carer. Children become “young carers” when levels of care giving (to the person in need of care) involves a level of responsibility that is inappropriate for the child and impacts on their own emotional or physical well being. It has been established that many young people in BME communities take on caring roles in excess of their age, and in addition many are expected to act as interpreters or language support assistants (e.g. translating letters and helping with forms in English), even when their fluency in their parents’ and grandparents’ language is slight.

While most children and young people help out parents to some degree, many take on caring responsibilities for family members that would be inappropriate for a child of any age to undertake. They may be caring for siblings, grandparents and parents. They are often responsible from a young age for tasks such as intimate or personal care, helping someone to get around, household tasks such as shopping, cooking, cleaning and paying bills, giving emotional support and helping to look after younger siblings. However, it must be remembered that not all children in families where a member has a disability will necessarily be young carers, although older siblings may also take on roles in caring for the younger ones. Because of the larger size of many Asian families, this is more likely to be the case in these ethnic groups.

Being a young carer can have detrimental effects on young people, including problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems a secret, problems with transition to adulthood, lack of recognition and feeling they are not being listened to. Many young carers

have problems at school, including poor educational performance and difficulty fitting in with their peers. Such problems may be a consequence of poor attendance at school and the pressure and stress caused by caring responsibilities. These may exacerbate the difficulties faced by some minority young people in school, either because of lack of support at home with their schoolwork, or because of different expectations between school and the home community – as well as the well-established facts of education and material deprivation that affect many young people from migrant and minority ethnic communities. In addition, when families include someone with a disability the family income is likely to be lower than the average and this may affect the young persons opportunities for further education, especially when (as is the case for most BME families), their incomes and wealth are already below the national average.

Carers from the younger age groups are significantly more likely to suffer with ill-health than the non-carer population. Children should not be expected to give inappropriate levels of care to family members who are ill, disabled or experiencing mental distress. Long term effects on young carers include impacts upon their personal and physical development as well as their educational and social opportunities. Research has shown that caring responsibilities during childhood may restrict career opportunities and life chances when they are adults. Previous young carers research has shown children from ethnic minority communities face added stigma such as substantial inequalities, discrimination and disadvantage from education, health and social services, often due to myths and stereotypes about their cultural background. Therefore it is not necessarily the case that their experiences of caring are any different from ethnic majority communities but it is the discrimination they face that can compound their caring role.

The Children's Society "Include" Project (formerly Young Carers Initiative) have developed Key Principles of Practice for working with young carers and their families and a Whole Family Pathway, a practitioners toolkit for providing good practice support to these families. The Principles highlight that the key to change is the development of a whole family approach and for all agencies to work together, including children's and adults' services, to offer co-ordinated assessments and services to the child and the whole family.

People with sensory impairment

Among the largest groups of cared-for people are those who have lost some of their abilities in relation to sight and hearing – and many of these are also carers in their own right. Statutory registration and rights are associated with these disabilities, but it appears that there is a mismatch between needs and provision even in such fundamental common issues.

Deafness and Hearing Impairment

Families supporting a child who is deaf express similar experiences to many other ethnic minority carers. They struggle to gain access to appropriate support. Various discriminatory practices - revealed in professional assumptions and organisational practices – make it difficult for parents to receive a timely and accurate diagnosis and obtain ongoing health, social and education support for their child. Parents are faced with

practitioners who associate deafness with first-cousin marriage, which not only seems to blame the parents for the child's disability but offers them little help in coming to terms with the diagnosis. Education, careers advice and employment support remain specific, longstanding problems for a child, whatever their age and this is keenly felt by their families. Parents face a particular dilemma when making a choice between mainstream and segregated schooling and express a need for greater support for service providers. Another major and more general problem is the extent to which service provision denies children the opportunity to express their ethnic, cultural and faith identity and is perhaps best summed up by a Bangladeshi mother's comments: 'I send my son to (deaf) school and he comes back an Englishman'. Parents express concerns that because of the communication difficulties they experience, their children might lack cultural resources to negotiate family life, made worse by their contact with a service provision informed by Eurocentric values. This is why some parents see the exclusive imposition of BSL at the expense of more multi-lingual strategies, as undermining their relationship with their child. Similarly, parents may have mastered some other means of communication (e.g. Makaton) and find themselves in conflict with professionals ideas about the hierarchy of suitability of these 'languages'.

The Deafblind UK BME Project

This project aims to promote Deafblind UK's services to the United Kingdom's diverse range of ethnic communities. It targets the following communities: Afro-Caribbean, Chinese, Irish and South Asian. It aims to recruit more members, carers and volunteers from a diverse cross section of society. The team's approach is to use BME events, BME media and visits to local authorities to reach out to minority ethnic communities in London and other big cities. They have also produced a range of leaflets in different languages which include Urdu, Gujarati, Bengali, Punjabi and Chinese.

Visual Impairment and Sight Loss

The care and carer needs of BME people in relation to low vision have had little profile in research or policy discussions. There is little awareness of race and culture issues in literature and guidance on low vision services, and equally awareness of low vision issues are missing from studies of BME health and social care. There is however no reason to suspect that there are lower levels of need among BME communities – indeed, in relation to certain forms of sight loss, there may be higher levels.

The Royal National Institute for the Blind (RNIB) estimates that there are about 80,000 people in the UK between ages of 18 - 64 years with severe sight loss (registered as blind or partially sighted). Numbers increase steeply with age, so that a study of the prevalence of sight loss in people aged 75 years and over found that 10% were visually impaired and 2% were blind. However, this age group is at present relatively small among BME communities.

There are a number of conditions which disproportionately affect BME people, and which will create needs for carer support. In particular people of African-Caribbean descent are eight times more likely to develop glaucoma than the general population and it tends to appear 10 – 15 years earlier than in other ethnic groups. Glaucoma is a major cause of irreversible blindness though it is avoidable with early detection and treatment. Similarly, Diabetes occurs up to 12 times more frequently in South Asian populations and is also raised in people of African-Caribbean descent) and is also associated with retinopathy and other sight problems.

It is also worth noting that 35% of visually impaired people report significant hearing difficulties and dual sensory loss (deafblindness) increases with age. 7% of people over 75 years have a moderate or severe hearing and sight loss and about 50% of those over the age of 80 who are visually impaired also have a significant hearing loss. We have no data on the incidence of this among BME people but it is very likely that people from BME communities are underrepresented amongst those who register as blind or partially sighted due to a lack of awareness of the registration process and the benefits of registration. Consequently, they and their carers are missing out on entitlement to benefits and services that are associated with being registered – such as 'blue badge' car-parking passes and reduced rate postage on 'items for the blind'.

- Generally, BME communities have a low awareness of the impact of visual impairment and what might be done to help.
- Visual impairment is often accepted as an inevitable part of ageing, or as part of ill-health generally.
- There is also an under-use of low vision services by minority ethnic groups and possibly under-registration.
- Health and care professionals, including specialists in visual impairment, may lack awareness of the needs of BME communities, while those with a good understanding of local communities often lack specific knowledge about visual impairment.
- Often people from BME groups are outside Social Care services, or may not be able to gain access to advice and information because of language issues.

Birmingham Focus on Blindness

Birmingham Focus on Blindness is leading a three-year Big Lottery Funded project (from July 2006) in partnership with RNIB, Action for Blind People, Thomas Pocklington Trust, Birmingham City Council and local health trusts. It aims to raise awareness within BME communities of sight loss and services and to raise competencies within sight loss services to meet the needs of BME users. They have held 4 sight-loss information fairs (the name was chosen when local people said they did not understand the term 'road-show'), at the Diwali mela, a Sikh temple, the Chinese centre and a local Hindu temple, and more events are planned. This will be achieved by holding Sight Loss Information Fairs with all partner organisations at community venues throughout the city. They are also developing the role of community champions for sight loss by training their Forum members/people from the local community who can then train others in their organisations and communities to be more aware of sight loss.

Key issues

- Voluntary and statutory organisations can hold events, health fairs and, where appropriate, clinic sessions in the community, choosing venues that people visit for other purposes. Many people feel more comfortable in non-clinical settings, such as community centres, local health fairs, cultural and religious centres etc.
- Providing person-centred care to BME people with visual impairment presents a challenge to service providers. BME service users tend to find that assessments of their needs fail to take into account issues such as language and culture alongside other needs.

Champion volunteers in Derbyshire Association for the Blind Derbyshire Association for the Blind (DAB) have recently recruited 4 "Champion volunteers" from local minority ethnic communities. These people will become expert volunteers – they will be educated in eye conditions and the services available. They will be trained to deliver talks and disseminate information in places they have identified. The volunteers will also advise DAB how to work better with BME communities.

New Communities

It is important to recognise that while there is now a growing body of research and other evidence relating to the needs of the settled BME population, many of whom were of 'New Commonwealth' descent and had a familiarity with the English language and British culture as a heritage of that history, much less is known about the situation of newer migrants to the UK. However, it is well known that migration and the creation of new minority ethnic communities has not stopped- nor is it likely to. While many recent migrants can find descendants of earlier migrations and settlers living in Britain, with cultural societies and community association, these may not be in the same places as the new settlement patterns, and new communities will still have to go through the same learning processes as their predecessors. Also, of course, service providers and carer support workers will need to learn about these new communities and their needs.

Recent research has highlighted the diversity of carers with which agencies may be working. This not only applies to carers' ethnic, religious and linguistic background but also their length of settlement and immigration status. An interview with a carers' support worker in the Black voluntary sector illustrates some of these issues.

"Traditionally, this area has always been a very much Black British community but we've got a huge Somali community and recently much more increasing Yemeni community. And looking at our facts and figures on the books, I would say about 20% of the carers are from the Yemeni community, which is a big proportion. It's a very small Asian community. We've only supported one or two families from the Asian community. Chinese community, I don't think we've got anybody on the books ... I don't think we've got anybody from the traveller

communities at the moment but we've got Russian people on the books, we did briefly have Afghani because there's a large Afghani community now. There was a big influx from refugees and asylum seekers... There's a lot of people from a variety of African countries, Rwanda, Zimbabwe, Sierra Leone. We've got a few people of those on the books."

On a practical level, those who have arrived in this country relatively recently may have difficulty understanding health and social care systems, knowing what support is available and how to access it. Situations may be further complicated by language barriers, lack of social networks and unsettled immigration status.

When I came to Britain in 2000 I didn't understand how patient confidentiality worked in the UK system. It was hurtful to be 'shut out' of my husband's care. I was denied involvement in consultations even after my husband had asked his psychiatrist for this..

According to official UK government estimates, approximately 1,500 migrants arrived to live in the UK every day during 2005. The same figures suggest that 185,000 more people immigrated into the UK than emigrated to another country, yielding a net population gain of 500 per day. Although the number of those arriving was lower than the levels reached in 2004 high levels of migration continue, particularly from Eastern Europe and areas of instability that are continuing to generate asylum seekers.

We had worked very hard when we first arrived in the UK, and had assumed that the first signs of mental health problems were really just tiredness or 'wear and tear'.

Some of the most striking figures relate to the eight Eastern European nations (the 'A8' states) that joined the European Union in 2004. 80,000 people officially came from the 'new accession' states for at least a year in 2005 and of the 1.42 million total number of immigrants who have arrived in the UK since May 2004, 427,000 were people registering to work from those former Eastern Bloc countries, with the vast majority coming from Poland. There are no figures for the number of children or spouses accompanying the self-employed, but the registered workers brought with them 36,000 dependants, although the majority are single people and do not bring 'carer' responsibilities with them, instead seeking to repatriate their earnings to family members left behind. The number of asylum applications has since fallen back to levels on a par with the early 1990s, with 23,520 applications received in 2006 (Home Office 2007). There have also been significant inflows of foreign students coming to study at British universities, and of migrants moving to join their families in the UK.

At this stage it is unknown what proportion of these migrants remain in the UK at any one time, particularly since many of them come to the UK to undertake temporary jobs in sectors such as agriculture and food processing. It is unlikely that many will form households with care

responsibilities, but it has been suggested that just under one quarter of migrants from Central and Eastern Europe plan on settling permanently in the UK, a much lower proportion than is the case with previous groups of immigrants.

There has been some debate between the Government and local authorities concerning the interpretation of the EU Directive which outlines the rights and entitlements of 'A8' migrants to social housing and homelessness assistance. Under EU Directives the citizens of the A8 states, Cyprus, Malta and the remainder of the EU have freedom of movement across the EEA and free access to the labour market in the United Kingdom. However, nationals of these states are subject to the UK's transitional regulations until May 2009, which state which classes of EU nationals have different types of right of residence, and state that "people can lose right of residence if they are an unreasonable burden on social assistance". Different criteria apply to citizens of the 'old' EU countries and those of the new states. Citizens of the 'old' EU countries obtain the right to reside if they are a worker, a job-seeker, self-sufficient, self-employed, a student or a family member of any of these classes. Citizens of the new states need to be a worker (and registered on the Worker Registration Scheme (WRS)), self-employed or self-sufficient, in order to have the right to reside. Different regulations also govern access to benefits in the UK. 'A8' nationals must be in work and registered on the WRS in order to claim in-work benefits, such as Housing Benefit. When they have worked and have been registered on the WRS for 12 months they can assume the same rights and entitlements as 'Old EU' states nationals. Regulations governing access to social housing and homelessness assistance are somewhat different in Scotland.

There are a number of agreed factors affecting the impact of the newest groups of migrants on UK society:

- They are predominantly employed low wage sectors – most typically agriculture and hospitality and catering.
- There is a tendency by migrants to work in jobs well below their educational and skill levels. Migrants accept this because the wages they earn in the UK are significantly higher than wages in their own countries (even if the cost of living is also higher)
- New migrants are generally young and fit, and have few dependants – and intend to return home to rejoin their families
- Migrants to the UK generally come to look for work due to high levels of unemployment in countries of origin. There are no trends to suggest that most are staying or intend to settle in the UK.
- Migrants make very few demands of the UK's welfare system.

However, a significant proportion of recent 'new migrants' are young people (aged 18-34). If the tendency is for young migrants to stay in the UK, there is also the chance of this group further integrating – having families and accessing a wider range of services as a result, although it is less likely that they will bring older relatives and consequent care responsibilities with them. They may, however, start to be carers for children, and those of their community who suffer work-related injuries, since many are in primary and risky occupations such as agriculture. The

main concern in relation to these groups is the increased vulnerability that most migrants have to poverty, racism and social marginalisation. Migrant admission policies are generally not coordinated with strategies to facilitate social integration. Further, these policies often do not coincide with national categories of eligibility to key services and social protection. Therefore, carer support and homelessness services do not necessarily have the resources or expertise to fulfil this safety net role adequately.

These concerns may be mitigated by the probability that the large majority of new migrants – in indeed of many asylum seekers and refugees, is that they will in due course (and not far in the future) seek to 'return home'. However, past experience of earlier migrations has been than a significant proportion will become settlers, and will need to overcome the hurdles posed by accessing carer support and other welfare systems, and make their own particular needs in terms of cultural and linguistic specificity on the capabilities of support services. It remains true, therefore, that more research is needed on this topic, and that in the interim, service providers should prepare themselves for new groups of users and their needs.

Refugee and Asylum Seeking Families

The health problems of asylum seekers are not always specific to their refugee status, and are shared with other deprived or excluded groups. Physical and mental health problems can include diseases linked to poverty and overcrowding, whether they are communicable diseases such as Tuberculosis, Hepatitis (A, B or C), HIV and Aids, or parasitic infections and physical injuries sustained while seeking refuge. Psychological and social health problems such as experiencing anxiety, depression and panic attacks and poor sleep patterns also affect them. They may have problems with memory, concentration and disorientation, which could hinder learning, including learning a new language. They could also suffer with stress related physical health problems such as heart disease and cancer, and could have an increased susceptibility to infection, as well as suffering from the effects of war and torture such as landmine injuries, amputated limbs, a loss of vision and hearing, injuries relating to beatings and torture and malnutrition.

It should be remembered when assessing the level of support and service provision needed by refugee families that they will not have the kind of support from extended family or community that the resident population may have. Nor will they be familiar with the range of services that may be available to help. They may also be unaware of their rights to health care, or the proper routes to access these, especially since the 'gatekeeper role' of the GP is a peculiarly British way into specialist care. All asylum seekers and refugees are entitled to primary health care services. They are also entitled to secondary care, except unsuccessful applicants for asylum whose entitlement will be decided based on individual circumstances.

There are certain barriers to health and social care services that need to be overcome. Language and cultural differences can present great barriers. The cost and availability of interpretation, translation and

advocacy are issues frequently raised by practitioners. There seems to be a lack of interpreters and particularly medically trained interpreters. The responsibility for translating often falls on other family members. The use of family, friends and other asylum seekers as informal interpreters should be discouraged as it denies patients the right to confidentiality within their family or community. Such barriers to healthcare show a piecemeal healthcare support service. It stands to reason that with these barriers care needs will be missed when undertaking assessments and providing support. This can adversely fall upon other members of the family, including children, or local community with detrimental affects.

Carers from refugee and asylum seeking families will be coping with the effects of caring as well as worrying about the family member who is disabled or unwell in a strange culture, surroundings that are unfamiliar, and a new language. These effects alongside the stigma and unsettling situation of being a refugee in a strange land compound each other and can be detrimental to their own health and their successful transition into the community.

Young Carers who are claiming asylum are particularly vulnerable. At a crucial time in their lives, they will have suffered significant upheaval including disruption of their education. The traumas that they have faced may adversely affect their social development. Their development and social inclusion can be compounded by their caring responsibilities and create further exclusion. Effective integration into their new community could help develop these skills but requires carer support to be aware of these competing demands, and to provide additional personal support.

Young people in refugee and asylum seeking families can find they are carrying out translation services between their families and support services; including translating medical information between the health services and family members who may be chronically sick or disabled. It is important to be aware of the impact of using children as interpreters. There is a need to develop protocols for decisions about using children in this role and clear guidelines of when it is not good practice to do so.

It is worth noting that whilst asylum seekers are excluded from mainstream benefits they may still be entitled to community care assessment and some aspects of community care provision (*Westminster County Council v NASS* 2001). In some cases, the local authority has a duty to provide accommodation and/ or support for asylum seekers and their carers. However, workers' confusion over entitlement often leads to no service at all. If workers are aware of the legislation they can use it to advocate for asylum seekers' rights. (Policy Bulletin 82 'Asylum Seekers with Care Needs' (NASS, 2004) is still applicable.)

Lessons from research

Census data

The 2001 census gave people the opportunity to identify their ethnic origin, and demonstrated that across the UK, one in twelve people (7.9%) stated that they belonged to one of the minority ethnic groups. While heavily concentrated in urban areas, and less prominent in Wales and Scotland (except for populations in Glasgow, Edinburgh and South Wales, where there is a very-long-standing community of Somali origin in Cardiff, for example), there is now no part of Britain where there is not a significant presence of minority origin. Indeed, in England, one in eight (12.5%) of the population identified itself in 2001 as belonging to a minority group (including Irish and 'White Other'). Even in the North-East region, where the smallest BME population is found, one in twenty (5.4%) of the population is of minority origin. In major urban areas, there are places where the 'BME community' in fact represents a majority: in London, boroughs such as Newham (66%), Brent (60%) and Tower Hamlets (57%). In major metropolitan cities such as Leicester (37%), Birmingham (32%) at least a third of the population is of minority origin, while one in five of the population of Manchester (21%) also gave their ethnic origin as of BME background

More recent estimates for mid-2005 suggest that the BME population has continued to grow, so that now over 15% of the population of England would belong to a minority group (i.e. other than 'White British'. There has been a particular growth in the 'mixed heritage' group, most of whom are young – but now make up 1.6% of the total population (and 3.7% of those aged under 15). For these groups, there will be in the future some new needs in respect of carer support. Equally, at the moment, there are still relatively few people from the BME population of pensionable age. It is at this point that care needs (and the need for support of carers, whether younger people supporting their parents generation, or older carers of spouses and relatives) tend to increase rapidly. In the majority 'white British' population, one in five (20.2%) is aged over 60 (female) or 65 (males), compared to less than one in thirteen (7.2%) of the population of South Asian or African-Caribbean origin – who make up a mere 3.9% of the total population of retirement age. As earlier migrants grow older in Britain and do not return to their countries of origin but stay close to their families here, these numbers – and their carer-support needs – will increase significantly over the coming decade.

The census did ask a question about whether people were providing care. Overall, one in five households said they were doing so, and 5.5% were providing over 20 hours of care per week. The figures show that almost the same proportions of BME households are providing care for someone, despite their much younger age profile. Indeed, a quarter of South Asian households said that they provided this sort of care, and were providing much the same level of support. Against stereotype, it can be shown that young Bangladeshi and Pakistani men and women are three times more likely than white younger people to combine paid work and caring. One in eight young Pakistani and Bangladeshi men (aged 16- 29) who are in

employment also provide unpaid care compared with just one in twenty five young White British men. One in seven young British Pakistani and Bangladeshi women who have a paid job are also carers, compared with just one in twenty young White British women. Among mature working age people (aged 30- state pension age), rates of caring are highest among Indian men (15%) and Pakistani women (19%) and are lowest among Chinese men (6%) and women (9%). While it seems that African-Caribbean homes were also less likely to provide care, their family sizes are much smaller and it appears that carers in these communities are more likely to provide care for someone living in an independent household – i.e. on their own, which was not counted by the Census question.

It is also important to note that while BME elders are relatively small in numbers, this population also carries a high health care burden. Children in BME households also have higher rates of need: 6% of British Pakistani and Black Caribbean children and children from mixed groups have a “long-term limiting illness”, compared with just 4 % of White British children. Many of the early migrants were employed in arduous and poorly paid or risky jobs, and a high proportion suffer from industrial illnesses, or diseases associated with poverty and poor housing. For various reasons also, there are very high levels of diabetes and cardiovascular disease affecting these populations, which mean that they have high risks of developing disabling conditions. Since there is little knowledge or awareness of services or familiarity with what can be done for those growing old in Britain, uptake of rehabilitation services, and of preventive care (such as eye checks, physiotherapy, mental health counselling) is low, and many disabilities are believed to be the natural and inevitable effect of ageing. This places additional burdens on the family carers, who may not know of, or be too proud to seek, assistance that is taken for granted in the majority white population.

Existing research on BME carers: Some emerging issues

Previous research has shown that the invisibility of care giving affects carers from all ethnic backgrounds. Carers are rarely the focus of services, their position is ill-defined and they are commonly marginalised in service delivery processes. However, BME carers face additional barriers of ethnocentrism and racism and this forms part of their experience with services. For BME carers there are two relationships at play: the general relationship between carers and service provision and the relationship between BME communities and service provision. Racism (whether it emerges at individual or institutional level) may therefore be at the heart of the issue of under-use of some services by BME communities.

In an analysis of carers' situations based on longitudinal data from the British Household Survey, Hirst (2004) demonstrates that the adverse effects of caring are not something that affects all carers, but are associated with particular circumstances and relationships, as well as gender. It follows that a failure to distinguish between sub-groups of carers will give inaccurate and misleading results without useful application. Hirst concludes that “much more needs to be known about health inequalities among minority ethnic carers to inform policy thinking

and service development". The issue is urgent as the current demographic trends shows that BME communities are aging faster than society at large (but that they and service providers have had little experience of looking after an older population from these groups in the UK). In particular, an age 'bulge' is working its way through the system of those who entered the UK in the late 1950s and early to mid 1960s, settled as UK citizens and had families, which means we are looking at a significant increase in the population of older people from BME communities who will need care.

An early literature review of research on BME carers found that caring was associated with extra costs and restricted opportunities for education, employment and promotions. In addition, people from BME backgrounds have lower average incomes compared to others and the quality of housing among BME communities was found to be considerably worse than the rest of the population. This is bound to have impact on their situation particularly since it is more common among people from ethnic minorities compared with others to live in the same household as the person they look after. This could also mean that there are few opportunities for respite in everyday life.

Lack of information about available support services is reported as an issue affecting BME people. There are a number of reasons why this may be the case: people may not seek information about support because care-giving is perceived as the family's responsibility; information is not given in a culturally appropriate way; there are language barriers between service providers and caregivers; issues of social isolation, and concealment of illness due to stigma. Further, as highlighted above, the term 'carer' itself as a relatively new term in social policy which may not have resonance in minority languages.

In policy circles, it was presumed that the implementation of community care would pose few problems in South Asian communities, due to the perception that strong networks of extended families would be available to provide support. Such presumptions are also reported by others, but research has shown that caregivers in these communities are generally unassisted by those outside their immediate family. A range of issues impact on traditional family organisation including strict immigration laws, a growing preference for living in nuclear families, occupational mobility and housing problems. Fragmentation of family networks impacts on where carers are available and issues such as gender, class, employment status of the carer and their integration into such networks impact on the support they are receiving. Negative attitudes and stigma may also influence help-seeking behaviour.

Our son was seen, in my presence, by an impressive young community mental health team [CMHT] doctor but sadly it was his last day in post. (He - the son) was in an agitated, but friendly state, swearing profusely which really surprised me. No medication was prescribed when he returned to college. The next appointment, a few weeks later, was with the senior house officer (SHO) in the same CMHT who was provided with two A4 sheets which contained almost all we noticed that was unusual and inexplicable about his behaviour. He would, for instance, travel only at

night and said he 'knew' that we could read his mind! The SHO glanced at my notes and looked at me as if I had committed a crime! She and an intern were with him for about 15 minutes and then I was summoned and told: "You Asian parents are over protective...there is nothing wrong with your son....send him back to university." Once outside, (my son) said: "See dad, I told you that there's nothing wrong (Shortly after this, the young man attempted suicide.)

The most recent research commenting on the situation of BME carers has just been published by Carers UK (Yeandle et al 2007). In their survey of around 2,000 carers in England, Scotland and Wales, nearly 10% were from minority ethnic backgrounds. This research found that compared with other carers, carers from BME communities are:

- More likely to report that they struggle to make ends meet
- More likely to be caring for their children, particularly children aged 20-25
- Less likely to be caring for someone over the age of 85
- More likely to be caring for someone with a mental health problem
- More likely to say they are using Direct Payment arrangements to pay for services

BME carers are also more likely than other carers to say that they were unaware of local services, that services were not sensitive to their needs and that their use of services was limited due to cost or a lack of flexibility. A number of people made comments about a lack of cultural appropriate support and services, although when present, it was much appreciated, even if things did not always run smoothly.

'We have carers support service at local level. Asian language speaking staff have enabled us to access benefits, housing and community care support service. My wife accesses domiciliary care support (Asian language speaking staff). But this service is not consistent because different workers come on different days which is disconcerting for my wife'

Current research points to the need for an urgent need to develop services which fully take into account the situation of BME carers and which involve them in service development. Some helpful advice as to how to achieve this has been published. In brief, these guidelines advocate that:

- Members of Primary Health Care Teams (PHCTs) should communicate with carers in a form which carers can understand
- Carers should have access to information about the full range of services offered by the PHCTs
- Team members should acknowledge the role played by informal carers in providing care for sick and disabled people
- The team should know which of its patients are carers
- Members of PHCTs should be aware of the range of services other members of the team are able to offer to carers

- Carers should be treated as individuals in their own right, their individual needs being recognised with regard to cultural and religious beliefs
- A basic patient-held continuous record should be kept at the disabled person's home to facilitate the coordination of care provided by different health professionals. This is particularly important when language differences are an issue, and there are now facilities to provide such information in minority languages, including web-based translated information (www.library.nhs.uk/ethnicity)

In summary, despite an increased focus on carers in current research and policy, there is a lack of research into the experiences and needs of carers specifically from BME communities. What research does exist is often focused on a specific geographic area or ethnic group. The current knowledge gap means that not only can existing research on carers lead to misleading conclusions and ineffective practice because it does not tell us enough about sub-groups of carers (Hirst 2004), it also makes it problematic to forecast the effect of future policy. As Katbamna and colleagues (2004 p 398) point out, "there is a lack of understanding about the possible impact of the reform of community care policy on minority ethnic communities". The identified need for more knowledge, in particular for quantitative national research, is addressed by the research of the Black Carers' and Black Carers Workers' Network.

Main findings from our research

The following responses are based on the first 300 responses that we received to our survey of BME carers across Britain. Responses came from all regions, and from carers of all types of cared-for people. We had replies from nearly all the minority ethnic groups represented in Britain. Just over half (58%) were of South Asian origin, 29% African-Caribbean (or Black British), and 5% Chinese: a quarter each from the three major faith groups: Muslim (27%), Hindu (26%) and Christian (25%) and 8% Sikh. Only 19 (6%) said they had 'no religion.

The 302 carers in this study lived in the following regions:

Yorkshire and Humberside: 24, North East: 13, North West: 70
 East Midlands: 80, West Midlands: 54, East of England: 4
 London: 25, South East: 23, South West: 9

What have black carers told us?

The voluntary sector organisations play a key role as gateways to information, support and services.

The research revealed a clear preference for carers from BME communities to be contacted in a personal, face-to-face way. Using outreach is one successful method for accessing communities who are

considered to be 'hard to reach'. However, many black and ethnic minority communities are unfairly labelled as 'hard to reach' by organisations who are unwilling to commit the necessary resources to reach and engage with them, and we prefer 'easy to overlook' as a description of these groups!

The carers who responded to this study were in many respects untypical in that most were already in contact with voluntary agencies. Voluntary agencies working in BME communities play a key role in providing information to these communities and enabling their voices to be heard. However, it became apparent in this research that the information organisations give can only be as good as the information they are given. It was apparent that carer organisations and those experienced in carer work provided comprehensive information about carer's rights and the latest government policy initiatives on carers, but were often (self-confessedly) ignorant of the specific needs and concerns of BME people. By startling contrast, voluntary organisations which did not have expertise in carer work were unable to offer anything like adequate information and in many cases seemed unable to offer basic information about accessing community care services. This was shocking. Organisations working within ethnic minority communities have a responsibility to inform people about and signpost them to community care services regardless of whether this is accessed through Primary care or Local Authority community care services. This situation should be urgently addressed by commissioners who should ensure that all voluntary agencies, especially those working in minority communities where English may not be the first language, should have the capability of informing and signposting people to services.

The importance of the voluntary sector in terms of accessing and informing carers was highlighted again and again throughout this research. This has major implications for commissioners of both health and community care services who have difficulty delivering their race equality strategy objectives without the support of these organisations. Equally, it will be harder to deliver the personalisation agenda for social care if people have poor knowledge of their entitlement to assessment and eligibility for community care services. Therefore, it is in everyone's interest if voluntary agencies working in these communities are kept well informed about the health and social care agenda and if they employ workers who are knowledgeable and skilled in informing people and signposting them to community care services.

'An organisation from the Black community that filled all the forms in, came out to see my parents, found housing suitable to their needs, provided care in the home, was prepared to make all telephone calls and chase everything up...this is how I managed' A Black Caribbean woman who managed to remain in full time employment despite caring over 50 hrs a week for over 10 years for 2 parents with long term health conditions

Black carers found it hard to identify with the term 'carer' as it is commonly used by service providers

Carers from Black and ethnic minority communities were especially confused by the concept of carer and found it hard to identify with the term or recognise it as a formal role.

The distinct role of 'carer' is a difficult one to understand within black and ethnic minority communities, where there are pre-existing cultural expectations around care giving, especially in old age. The added confusion for BME carers about what constitutes 'care giving' was a recurring theme throughout this study with some carers finding it impossible to identify how long they have been caring or how many hours of 'caring' they contributed each week, even in situations where they were supporting a severely disabled child or disabled spouse with a very high level of care needs.

Black carers have poor knowledge of services

Carers from BME communities had poor knowledge of statutory sector provision of services and often expressed their lack of confidence in the statutory sector's ability to provide culturally relevant or appropriate services. The carers in our study were very reliant on voluntary sector agencies for service provision, which reinforced their perception that mainstream services were not designed for them. Many of the carers seemed unaware that these voluntary agencies were commissioned by or funded from the statutory sector purse. The fragile and temporary nature of much voluntary sector funding served to reinforce this perception that services for BME communities, including carers, are not given equal priority as services to the white community.

This poor knowledge of services had a significant impact on the findings in the study. We found that carers were unable to comment on what they wanted in terms of services. Such findings could inadvertently give the impression that BME carers were not in need of services where, in reality, carers with no experience or knowledge of services felt unable to imagine how services could help them. In the study it became clear that carers in receipt of services were more likely to ask for more of the same services or would suggest how that service could be made more culturally relevant.

Black carers wanted the personal care services delivered to the person they supported to be more culturally relevant.

The carers in the research highlighted many situations where personal care services failed to take into account the following needs:

- Language needs
- Dietary needs, especially in 'meals on wheels' and for inpatients in general and psychiatric hospitals (including both religious and cultural aspects, such as the use of spice, or vegetarian options)
- Personal care needs which included the timing of baths, dressing (assisting someone to put on a sari) and hair and skin care (for African Caribbean people)

Black carers valued services enabling participation in community events

Many carers, especially from the South Asian communities wanted services to support them in playing an active part in their communities by attending festivals, family events and attending places such as mosque, church or temple. The ability to perform religious duties including prayer was seldom recognised or supported by existing services.

Two South Asian carers said that their children and grandchildren had been disappointed when they had not been as involved as expected in arranging their marriages. (carers of person with mental health problems)

African and African Caribbean carers were more concerned with peer support and having the option of company and culturally relevant activities with others within their community (such as dominoes and sewing). This group were far more likely to access mainstream leisure and other facilities.

BME carers felt an especially strong identification with their community of ethnic origin which showed itself in a strong sense of duty towards that community. BME carers emphasised how important it was for them to feel part of their ethnic community and consistently described their preference to spend their time participating in shared culturally relevant activities rather than pursuing 'leisure' activities such as clothes shopping, going to the gym or library, attending coffee mornings, meeting for lunch, going to pubs or clubs, walking, or even hobbies such as train spotting or bird watching. This is not to say that BME carers do not enjoy all such activities: it is simply that they are expressing a strong preference for services to support them and the person they care for, in playing an active part in activities within their own cultural communities. This was important to both their sense of belonging and as a way of keeping their cultural traditions alive.

In contrast to the strong desire for services to support community activities South Asian carers did not express interest in attending mainstream leisure activities such as gyms or libraries. Equally going to the theatre, clubs, cinemas, restaurants, cafés or even hairdressers was never mentioned. Religious and family or community events took the place of these activities in their daily lives. This suggests that outreach will be required to encourage access to health and other leisure facilities traditionally provided by local authorities.

The impact on BME carers from the lack of culturally relevant services

The additional difficulties in accessing services impacted on BME carers in a number of ways:

- Poor mental and physical health
- Additional difficulties around remaining in employment, education and training

Many of the carer concerns identified in the study around employment were typical for all carers and not confined to black and ethnic minority carers. It

was also noticeable that the carers who were most able to remain in full time employment were often in situations with flexible working hours (such as Local Authorities). Carers documented having to forgo training, studying and career opportunities or progression. Such experiences are shared by many carers.

That said, carers supporting older parents who did not speak the language or who have different cultural traditions faced additional barriers in accessing acceptable support for the person they cared for. This meant that they often ended up relying inappropriately on other family members for help or they had to give up work. Carers described having to use their lunch breaks to take appropriate food into hospitals, or rush home every lunch-time to make meals. This placed additional and unacceptable burdens on BME carers which other carers did not have to face.

'I need someone who speaks Shanghai Dialect to help me to care for my father if I am too busy in my shop but unfortunately social services do not provide this' Chinese woman working full time while caring 50+ hrs a week.

The personalisation agenda and the use of Direct Payments by black carers

9% of the carers in this study indicated that the people they supported were in receipt of direct payments to purchase services. 84% reported that the people they cared for were not and 5% said they were either unsure or didn't know.

Direct payments are confusing for both service users and carers and especially so for people with little experience of the community care services they are designed to replace. The carers in this survey, in common with many others, were unsure whether the Carers Allowance and other welfare benefits were direct payments.

In this study we tried to distinguish between those carers who regularly used direct payments to purchase carer support services with those who were given a one off payment for a holiday or breaks service which would be classified by their local authority as a 'direct payment'. We discovered that 13% of the carers in our survey reported receiving one off payments whilst 6% said they were regularly in receipt of direct payments in lieu of services.

Mainstream or Separate Black Services?

The low take-up by minority users, and Eurocentric nature of mainstream services raise political and policy issues about whether appropriate provision should be through mainstream or separate Black services. It has been argued that in order to address racism, social policy, legislation and service provision must confirm that Black people are within mainstream society. In other words, that support for BME carers should become a mainstream issue for all relevant agencies. However, studies have indicated that the principle of mainstreaming is often synonymous with a generalist approach, which disregards the needs of BME people. Guidance

accompanying the 1999 National Carers Strategy and subsequent carers' legislation has contained little direct reference to BME issues with correspondingly poor outcomes for this population

It can be difficult for people from minority communities to speak their mind about services. I have often been told to 'go home' to my country of origin if I am not satisfied. Service staff are often unaware of the importance of cultural differences and don't have a clue about how we live and express ourselves and how we do things differently'

Research suggests that mainstream organisations are often lured by funding for BME issues but lack the commitment and strategic planning to integrate Black carers' needs into mainstream services. In order to improve the quality of services, organisations have employed staff to work exclusively with minority communities. The experience of many of these workers mirrors the effects of institutional racism since they encounter isolation and lack of support in time-limited projects with minimal funding.

Historically, the Black voluntary sector emerged to address mainstream inadequacies and has assumed a political, anti-racist significance, campaigning for rights, representation and self determination. Studies have highlighted the advantages of an independent, ethnic-focused sector for service users such as accessibility, cultural and linguistic relevance, expertise and proactive awareness of needs. Community groups provide a locus of cultural identity and cohesion and play an important role in mediating between service users and mainstream institutions. It is argued that Black voluntary organisations are the best means of promoting the social inclusion and civic engagement of Black communities. However, while the Black voluntary sector does address specific needs, it operates at the periphery, reflecting the overall marginalisation of oppressed groups. Racism increases the need for this sector but 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. The prevalence of short-term funding reflects tokenism and lack of commitment to long-term service provision.

Further, and of great concern for welfare services, such community-based organisations often have a strong cultural and religious focus, which is a strength but may mean that some existing stereotypes or stigma associated with disability or impairments and disability are not challenged, or are hard to manage. Further, the focus on religious or cultural objectives, and dominance of certain groups within society, may mean that awareness of welfare rights and needs, and advocacy on behalf of more vulnerable members of the community, takes second place to the main agenda. Indeed, many community leaders may be unaware of their obligations (and the opportunities available to their members) associated with disability and caring roles. It is therefore essential that, should agencies and authorities choose to work through, or delegate their responsibilities to, minority community organisations, that they should provide education, training and support in such matters as supporting

people with welfare needs, and accessibility for those with disabilities. This might include help in drawing up 'equality impact assessments' and training in practical skills such as guiding a blind person or making buildings accessible.

White British professional carers don't look after my sister's hair and skin properly.

Services and Initiatives that are not appreciated

Equally, it must be recognised that not all initiatives and services for carers are wanted by carers in minority cultural communities. We observed that many Asian carers in our survey did not indicate that they gave or required help in 'Accessing leisure facilities' despite ticking every other caring role. This suggests that Asian carers would not choose to access facilities such as gyms or libraries. There was also a strong preference within this group to devote what would be considered 'leisure' time to attending family or culturally specific social events including religious festivals as well as attending mosques or temples. This preference is highlighted elsewhere in the survey as many Asian carers described their desire for a sitting or breaks service to enable them to attend family and community events or places related to their faith. The desire to attend gyms, libraries, theatre, clubs, cinemas, restaurants, cafés or even hairdressers were by contrast, never mentioned. Having an active social role within the Asian community was a priority for Asian carers and it should be considered a priority for service providers to focus facilities such as sitting services to support this involvement in religious and family events.

Revisiting the 'We Care Too' good practice examples

As part of its wider research remit, the NBCCWN steering group followed up the organisations and projects cited as examples of good practice in 'We Care Too' (NBCWN, 2002). We wanted to know if these had been able to survive the inconsistent and competitive nature of statutory funding since this is a risk factor for most Black voluntary sector organisations. A second objective was to identify other factors, which facilitated opportunities for development or acted as constraints. The original examples were drawn from across the statutory and mainstream and Black voluntary sectors.

We were pleased to find that the majority of agencies and projects mentioned in the Good Practice Guide were still in existence and continuing their work with Black and minority ethnic service users and carers. Some had altered their focus slightly to adapt to changing needs and five Black voluntary sector agencies or specific Black projects within mainstream organisations were no longer functioning. A few projects had been mainstreamed.

Funding

Perhaps the biggest barrier in the Black voluntary sector was short term funding. Insecure funding was not only demoralising but acted as a

constraint on forward planning and development. Whilst organisations recognised the importance of outreach to both new and existing communities, this sometimes had to be curtailed through lack of resources. Overall, the high up-take of services resulted in workers reaching capacity and many carers having to wait to access support. This contrasts with the disproportionately low-up take of mainstream services, which continues to be justified by the notion that 'Black carers look after their own'!

Some voluntary sector agencies benefited from a close working relationship with statutory sector providers and this tended to be reflected in funding, which was more realistic and secure. Sometimes support was linked specifically with mainstream professionals who understood the issues and had the political will to make an impact on mainstream policy and practice.

Status and Role

Unequal status was cited as an issue between the statutory and voluntary sectors and the mainstream and Black voluntary sector. This could lead to a dismissive attitude and an unwillingness to work collaboratively. Some workers experienced marginalisation and isolation within mainstream organisations. This could jeopardise a project's survival.

Whilst not all the agencies had a distinct lobbying and campaigning role, there was a sense in which Black voluntary sector organisations were engaged in raising mainstream awareness and challenging inequalities. Some took part in the training of mainstream staff. Organisations described an 'overseeing' role with regard to other agencies to ensure that carers received culturally appropriate assessment and support.

Good Practice Examples revisited

Alzheimer's Concern Ealing is a mainstream voluntary organisation, established in 1982, which provides innovative and culturally appropriate provision for service users with dementia and their carers. Since the 'We care Too' report 2002, it has opened a third multicultural weekend day care centre. The organisation has produced two videos 'Dementia Ki Hai,' 'What is Dementia,' in Punjabi and 'Dementia does not Discriminate'. They also have a Dementia Café, which offers a safe environment for visitors, service users and carers. The board of trustees consists of current and former carers and the agency is assisted by volunteers including ex-carers.

Age Concern Sandwell has continued to provide culturally sensitive services for older people from BME backgrounds.

Anika Patrice is a voluntary agency in Stoke Newington working with Black and minority ethnic service users with disabilities and their carers. It has survived funding crises by training volunteers, who facilitate four evening sessions of respite care each week. Referrals are from various sources including General Practitioners and social services.

The Asian People and Disabilities Alliance has expanded its services and relocated to a new property in Wembley. This agency is run for and by Asian people with disabilities and their carers. Its projects include day care, sports and leisure, befriending and advocacy.

ASPANETH is the Asian Parents Association for Special Education Needs in Tower Hamlets. This organisation works in partnership with the local authority and has continued to expand its services since 2002.

The Black Carers Project Bristol has recently celebrated its tenth anniversary and in addition to providing support for adult carers is now working with and raising awareness on behalf of young carers from Black and minority ethnic backgrounds.

The Black Training and Enterprise Group (BTEG) was established in 1991 and operates on a national basis. It has a capacity building team, which supports a number of BME voluntary and community organisations. Its main objective is better outcomes for BME communities in government policy and funding.

Bristol Family Link Scheme have continued to assist parent carers of disabled children by offering culturally appropriate respite care placements with families or individuals in the community, who have been trained to provide this service.

Coventry Carers Centre is a mainstream voluntary organisation, which has been working with Black and minority ethnic carers since 1995. It has attracted large numbers of carers through culturally appropriate outreach, consultation and support. The Asian worker's post has recently been mainstreamed.

Dudley Metropolitan Borough Council has continued to extend its outreach to minority ethnic groups within the area. It now has a specific post dedicated to developing services for people with learning disabilities and their families from BME backgrounds. The post holder has been working with carers to enable them to access mainstream services, raise funding and take group action. This has helped to reduce the stigma associated with learning disabilities and promoted community ownership of the issues. The initiative 'Ehsas Carers' were commended at the BMEspark Awards, which recognise excellence and innovation in responding to the needs of vulnerable people in BME communities.

Gloucestershire Carers is working with most of the BME communities in the city area and runs a number of carers' support groups. It has been particularly successful in establishing an Asian male carers' group.

Kirklees Health and Social Care was involved in the preparation of the original 'We Care Too' document and runs specific projects for almost all the local communities.

It was not clear whether the **Lambeth, Southwark and Lewisham Outreach Team** and the **Salaam Refugee Health Project** were still

functioning but the **Southwark Refugee Project** has been providing support and advice to refugees and asylum seekers since 1991. Agencies have formed strategic partnerships across the refugee sector in order to survive the difficult funding climate in London.

Lancashire Health and Social Care supports the Lancashire Asian Carers Forum. This has a strategic role in responding to the concerns of Black and minority ethnic communities.

Oldham Young Carers Project has continued to identify and work with young Black and minority ethnic carers. They currently comprise about 20% of the agency's client group.

OSCAR in Bristol provides services for people with Sickle Cell and Thalassaemia disorders and their carers. Services have expanded to meet the needs of those migrating to the UK from areas where malaria has been endemic.

Rethink Birmingham has specific services, which are responsive to the mental health needs of service users and carers from the local communities.

Tameside Health and Social Care has continued to work closely with local communities and is an example of best practice in its use of interpreting services and provision of information in appropriate formats. It runs culturally appropriate training programmes for carers and engages them strategically in planning services. The Maddad Ghar Project is a community support service for Asian carers and service users.

Waltham Forest Carers Association no longer has a dedicated Black Carers Support Worker but continues to work closely with local community groups to make sure that services are both accessible and appropriate.

Messages from the voluntary sector

In addition to revisiting the 'good practice' examples from the earlier study, we circulated a survey seeking more ideas for practice and exploring the experiences and capacity of voluntary and community organisations to meet the needs of carers. In total, we have so far received over 60 responses but had to disregard all but 36 because some were from statutory services and others were completed by workers who were involved in developing or supporting specific BME groups which had yet to be awarded funding. In many cases we felt that it was wrong to include the information from these groups as their experiences were not typical of mainstream voluntary organisations employing staff. Replies fell into four categories:

1. BME organisations whose sole purpose was to work within specified BME communities. These organisations usually worked with anyone within

that target community (both service users and carers) on a number of issues. There were 5 such organisations included in our sample.

2. BME condition specific organisations. These are voluntary organisations funded to work within specific communities in relating to one condition such as mental health. Again they usually worked with both service users and carers. There were 2 such organisations included in our study.

3. Condition-specific organisations such as Mencap, Rethink, Salford Heart Care or the Alzheimer's Society, whose funding was directed at working with people with a specific health condition. There were 9 such organisations included in our study.

4. Organisations which were funded to support carers either as Carer Centres or Carer Support services providing breaks to carers. There were 20 such organisations included in our study.

How secure was the funding for the voluntary organisations?

The majority of the Voluntary organisations (72%) in our survey were well established having operated for over ten years. This finding would have led us to expect that these organisations would have developed a longer term funding arrangement with their commissioners but the majority of the mature organisations were operating on core funding which was renewed annually. This situation was by no means confined to the black voluntary organisations but appeared to be a feature of all the voluntary organisations. The majority reported that their main source of funding was from the Local Authority with a few jointly funded by PCT's. BME organisations were noticeably more dependant on the Local Authority as their main and only source of funding, while the non BME specific condition voluntary organisations and the Carer Centres and Carer Support organisations were more likely to receive additional funding from the Local Authority Carers Grant, the PCT's and Grant giving organisations.

Almost half of the Carers Organisations were unsure about their future as a result of concerns were about the continuation of the Carers Grant, the challenging financial position of PCT's and reductions in voluntary sector funding overall. This seems ironic given the renewed priority given to carers nationally

Information about the needs of black and minority ethnic communities

A significant number of Carer organisations looked to local BME organisations and BME strategic networks as important sources of information. This highlights the key role that local BME voluntary organisations are expected to play in terms of distributing information and sharing knowledge about the communities they work in. However a major problem for many of these BME organisations is around their capacity to deliver this important service to other organisations. Many are funded simply to provide direct services rather than raising awareness and supporting other organisations to reach BME communities. Two carer organisations gave their main source of information as their BME outreach

workers, placing additional pressures on these workers to both deliver a service and lead on BME issues.

Given the central role played by local BME organisations and strategic partnerships as a source of information and expertise for the voluntary sector it was concerning to note that only three of the seven conducted surveys or research to find out about the specific needs of their communities.

Action taken to ensure equality of access

Not surprisingly all the BME organisations report taking action to ensure equality of access as did almost all of the other organisations in this study. These actions typically included a combination of provision of information in minority languages, employment of language competent staff, and (less often) outreach events to take information into communities.

'We have produced information in what were the main community languages, but this wasn't always useful without someone to explain the ideas e.g. "community care" or "assessment" and also because some carers weren't able to read the translated language. We did some very successful work with bi-lingual community workers (in the former family and community services department) and set up a Yemeni Carers Project, but this has recently ended because of lack of funding

Development of Race Equality Strategies

When we asked whether the organisations had a Race Equality strategy it became apparent that many respondents were unclear about the difference between this and the Equal Opportunities policy. These results show that all the organisations appeared equally confused on this issue and relevant training is clearly needed. However, a majority of the organisations did carry out ethnic monitoring by using the monitoring systems of their funders followed by the use of the Census categories.

The Afiya Trust / NBCCWN Good Practice Guide?

We were disappointed in that few organisations reported knowing about or acting on the 'We Care Too' good Practice Guide produced earlier by NBCCWN and Afiya trust. While awareness was greater generally amongst carer organisations only 44% of all voluntary organisations were aware of the guide. Some agencies did report that it had been effective:

- 'prompted a drive to reach out to more ethnic minorities'
- 'our carers strategy was very influenced by it'
- 'Helped outreach worker with work'
- 'The practice guide is implemented in relation to our organisations work'

Overall, it is clear that there is a need for considerably more support including training and networking between organisations to share good practice.

The final message – Summary and conclusions

A number of key messages emerge from this study and review. Some of these relate to more general needs of the carer-support sector, or are common to all voluntary sector organisations. However, all have implications for Equality Strategies and the needs of black and minority ethnic communities, including the growing 'new migrants' sector of the population, and the ability of the 'welfare state' to support people with care needs and their carers.

Overall, all respondents agree that there is a need for a more coherent approach to Strategic Planning, including the need for explicit attention to locating (for example in contracted out services) providers who can provide culturally competent services. All service providers need to demonstrate equality of access and service uptake and have a properly developed Equality Strategy. This will also require attention to Needs Assessment procedures which take the trouble to look into the specific needs of minority groups. These will not be effective unless communities are given training information to inform their choices, and empowered to be able to take part in the decision making process.

Similarly, organisations will need to ensure that they have a cadre of language-competent staff, and that they can improve communication with communities individually or as a whole, including providing *relevant* information in simple language in English and in mother-tongue languages. Planning this will require a good knowledge of the demographics of the area and which languages and cultural groups are most common locally. From this, training programmes can be developed for staff, since it is still not the case that professional education or initial training courses prepare workers for practice in multi-cultural settings. While such training can be provided by local community-based groups ('Black Voluntary Organisations'), these cannot be responsible for doing this on their own, or without funding and support.

Finally, it is essential that all organisations improve their Ethnic Monitoring. This means also training staff in its collection, and making sure that data once collected is used to plan services. Monitoring of the workforce will also assist in answering the question "Do you have a workforce which reflects the population you serve?" This may then lead to action to address the barriers to employment, and ensure job descriptions; adverts and recruitment processes are not discriminatory

After we moved, living close to his family didn't offer any better environment. In fact it only triggered more suicidal thoughts, panic attacks and violent outbursts. My husband and his family accepted the doctor's word "work related stress". But I discovered a life long history of his mental health problems which was never treated properly; history of bullying, racial and physical harassment at school, which were all kept as "family secret". My involvement as caring wife and discovering the family secret, brought some conflicts between me and his mum, unfortunately. And getting any support for this, was difficult. (Asian Wife)

Recommendations

For Health and Social Care Commissioners

On a policy level

- The use of the term carer is universally misunderstood and misapplied. In Black and ethnic minority communities this confusion works as a further barrier to deter carers from approaching services. Commissioners should take every opportunity to raise awareness of carer issues in a sensitive and appropriate way within these communities through the many avenues we describe.
- We would also endorse the Association of the Directors of Adult Social Services (ADASS) recommendation to the Department of Health in relation to the development of the revised national carers strategy:

'There should be a consistent nationally agreed definition of a carer in the National Strategy. Misuse of the term 'carer' causes much confusion and this can prevent carers becoming aware of their rights' (ADASS 9th Jan 2008)

On a commissioning level

Commissioners from statutory agencies need to ensure that there are regular 'reach out' events which provide face to face information to people from BME communities and their carers about the type of services they provide, their rights in relation to those services, and the role of carer. These regular events should be backed up through leaflets in different languages. Commissioners can show a presence at events which are already being organised in the communities by other organisations. If organising their own events, they must consider timings and dates/days which would be most suitable for the target group, for example, not holding events on a Friday for the Muslim community (especially men) as this is prayer time. Commissioners should be aware of the cultural rules and norms of local communities and plan events accordingly.

- Commissioners need to ensure that services for BME communities have not become separated from mainstream service provision and that mainstream services offer equality of access. Some targeted services can be used to encourage people to engage in the first instance and for BME communities to 'test out' services before committing to using them as a stepping stone into mainstream services.

In situations where voluntary agencies are commissioned to provide services to BME communities, commissioners should ensure that service users and carers are not being disadvantaged by this arrangement through a combination of:

- Inadequate or insecure funding for the organisation,
- The service being provided by low paid staff with less knowledge, experience or training.

- Poorly developed arrangements for referral or joint working with statutory services.

Therefore commissioners should ensure that workers in voluntary agencies are equally trained, informed and supported as any workers directly employed by either the Local Authority or PCT.

- Commissioners from statutory agencies need to ensure that voluntary sector agencies are fully supported in terms of funding and other resources in their key role as information givers to BME communities. Commissioners should also work with voluntary agencies to deliver regular joint interagency 'reach out' events or road-shows ('information fairs' – the term 'road-show' may not be meaningful in minority languages!) within the communities to both inform people about their services and those they commission and raise to awareness about carers.
- Health and Social Care commissioners should prioritise the provision of regular training to all voluntary, independent and private sector workers to ensure that every worker has the knowledge and skills to inform and signpost people to health and social care services.
- Health and Social Care commissioners should include the requirement that all staff should be adequately trained to inform and signpost people, in contracts or Service Level Agreements with voluntary, independent and private organisations (in much the same way that child protection training is compulsory for all teaching staff).
- Commissioners may wish to consider placing or seconding their staff to relevant organisations to encourage a shared learning of how to work better in the BME communities.
- Commissioners should ensure that the organisations they commission who come into contact with carers have at least one member of staff who is knowledgeable about carer's rights and services. Again this could be achieved by the placement or secondment of local authority or health staff within the organisation.
- Each Local Authority ought to undertake an audit of home care services to see if people who do not speak English as a first language have equal access to services provided in the same language as their English speaking peers.

For providers

- Aim to deliver home care services to people in the language they speak and to provide these services equally between English speaking and non English speaking people. This may include recruiting bilingual staff in specific targeted posts who are able to

deliver the direct care services to the people from BME communities who chose this linguistically and culturally supportive service.

- Ensure that all staff have appropriate training in cultural competence and can demonstrate at least a minimum understanding of the personal care and social care needs of the communities they are working in. Aim to provide services with staff who are knowledgeable about different cultures to ensure that the people they work with can participate fully in religious festivals and cultural events.
- More “same language” speaking staff need to be recruited and trained. If this is not possible, then voluntary or independent organisations should be commissioned to deliver this service with effective funding and support as above
- Good quality culturally appropriate food should be offered as a matter of course in day centres, by domiciliary care services and in all hospitals including psychiatric hospitals.
- Providers should aim to provide services in a way that supports attendance at important family events, community festivals and allow people to follow their religion. Some festivals and events take place over several days and this should be catered for. If the providers are unable to organise services to cover such events then direct payments should be encouraged.
- All carers should have the option to access a carer support group and social activities with other carers from their own ethnic group.

For researchers and those who fund research

There are clearly large gaps in the evidence base to inform better policy and practice, and to support development of services and training for service providers, as well as information resources for carers and potential users of services. We have identified few materials relating to carers from BME groups in most of the specialised ‘client groups’, such as ‘Young Carers’, carers of people with disability, sight or hearing impairment, and long-term conditions. There appear to be more developments around mental health and learning disability, although many of these are supported by short-term funding or individual initiatives. There are other client groups (for example, carers of people with drug and alcohol problems) and new ethnic groups including Somali, Kurdish, ‘Eastern’ European and other more recent migrant communities, whose needs also are yet to be met. Further, it would be desirable to support the collection and safe storage of many reports arising from short-term funded projects, to ensure that learning from experience is not lost.

In Conclusion

Needs are universal; solutions may be different

People and carers from BME communities mostly have the same needs as others. However, culturally sensitive ways of enabling people to access services are needed, and some services may need to adapt the way they are provided to meet the needs of particular communities. Different communities are likely to require different approaches to meet the same needs.

Sustain and mainstream BME provision

Services for BME communities are often set up on a time-limited project basis, and are not always properly evaluated. As a result, they are vulnerable when project-funding ends. When planning a service development, it is important to consider how the service will be mainstreamed if it proves to be successful. It is also essential not to rely on the enthusiasm of one individual or just a few people. If the developments are justified, they need to be owned by the whole organisation.

Monitor, evaluate and collect data

It is important to know who is using the service, and whether strategies to increase accessibility or reach out to BME communities are effective. If improved health or well-being outcomes can be demonstrated, services will be more sustainable. If interventions are not effective then resources can be redirected.

References

- Ahmad W, Atkin K (Eds) 1996 *'Race' and Community Care* Buckingham: Open University Press
- Ahmad W, Darr A, Jones L, Nisar G. 1998 *Deafness and Ethnicity: services, policy and politics* Bristol: Policy Press & Joseph Rowntree Foundation
- Ahmad W, Atkin K, Chamba R. 2000 'Causing havoc among their children: parental and professional perspectives on consanguinity and childhood disability', in Ahmad W. (ed) *Ethnicity, disability and Chronic Illness*. Buckingham: Open University Press.
- Ahmad W, Atkin K, Jones L. 2002 'Being deaf and being other things: South Asian deaf young people and identity negotiation. *Social Science and Medicine*, 55(10): 1757-1769.
- Ali N, Atkin K, Craig G, Dadze-Arthur A, Elliott C, Edwards A. 2006 *Ethnicity, Disability and Work*, London, RNIB.
- Atkin K, Rollings J. 1992 Informal Care in Asian and Afro-Caribbean Communities: A Literature Review. *British Journal of Social Work*, 22, 405-418.
- Buckner L, Yeandle S. 2006 *Who Cares Wins: The Social and Business Benefits of Supporting Working Carers (Statistical Analysis: Working Carers: Evidence from the 2001 Census)* Sheffield: Centre for Social Inclusion, Sheffield Hallam University, for Carers UK
- Carers UK 2002 'The History of Carers UK and the Carers Movement'.
- Chamba R, Ahmad W, Jones L. 1998 *Improving services for Asian deaf children*, Bristol, Policy Press.
- Clements L. 2005 'Carers and their rights: The law relating to carers ', London: Carers UK
- Communities and Local Government (2007) *The New Performance Framework for Local Authorities and Local Authority Partnerships: Single Set of National Indicators*: HM Government.
- Department for Communities and Local Government 2006 'Strong and prosperous communities'
- Department of Health 2005 'Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 combined policy guidance ', London: HMSO.
- Department of Health 2006 'Our health, our care, our say: a new direction for community services', London: The Stationery Office
- Hirst M. 2004. *Health Inequalities and Informal Care. End of Project Report*
- HM Government 2007 'Putting People First: A shared vision and commitment to the transformation of Adult Social Care'.
- Home Office 2004 'Firm foundations: The government's framework for community capacity building', London: Home Office. .
- Jones L, Atkin K, Ahmad W. 2001 'Supporting Asian deaf young people and their families: The role of professionals and services', *Disability and Society*, 16 (1): 51-70.

Katbamna S, Ahmad W, Bhakta P, Baker R. 2004 Do They Look After Their Own? Informal Support for South Asian Carers *Health and Social Care in the Community* 12(5), 398-406

Katbamna S, Baker R, Bhakta P, Parker G. 2001. Development of Guidelines to Facilitate Improved Support of South Asian Carers by Primary Health Care Teams. *Quality in Health Care* 10, 166-172

Michael Hirst 2004 Health Inequalities and Informal Care: End of Project Report SPRU, York University

Netto, Gina. 1998. 'I forget myself': The Case for the Provision of Culturally Sensitive Respite Services from Minority Ethnic Carers of Older People. *Journal of Public Health Medicine*, 20 (2), 221-226

PRIAE 2005 Black and Minority Ethnic Elders' in the UK: Health and Social Care Research Findings. PRIAE MEC UK Research Briefing, PRIAE: Leeds Social Care Institute for Excellence 2005 Practice guide 5: Implementing the Carers (Equal Opportunities) Act 2004 London: SCIE

Social Care Institute for Excellence 2005 Resource guide 5: Direct payments: answering frequently asked questions London: SCIE.

Social Care Institute for Excellence 2007 'Choice, control and individual budgets: emerging themes', January 2007.

Yeandle S, Bennet C, Buckner L, Fry G, Price C. (2007) *Diversity in caring: towards equality for carers*. Report 3, Carers, Employment and Services Report Series. London: Carers UK and University of Leeds.

Note: A full bibliography and additional information on sources can be obtained on request.

Other Useful Resources and Contacts

NBCCWN

The National Black Carers & Carers Workers Network has regional support networks in the North-West, East Midlands, and London. It can be contacted through the Afiya Trust, or directly to the regional workers. (For London: see Carers UK below)

(The) Afiya Trust

The Afiya Trust is a London based, Black and Minority Ethnic (BME) led organisation with a nation-wide remit to reduce inequality in health and social care provision for racialised groups. It seeks to address its mission through networking and partnership working, representation in the development and implementation of policy and practical change, community engagement, user involvement, support, consultations, research and information dissemination.

Website: www.afiya-trust.org

Afiya Trust

27-29 Vauxhall Grove

Lambeth, London SW8 1SY

020 7582 0400

BMECSS

The Black & Minority Ethnic Carers' Support Service is based in Tottenham (London Borough of Haringey) and is a London wide provider of services to BME Carers.

www.bmecarers.org.uk

Carers UK

Cecilia Tsang; Advice & Representation Officer - Black Carers, Carers London (part of Carers UK), provides quality advice on community care & welfare benefits and information to carers in London. Also co-ordinates the London Black Carers & Carers Workers Network (LBCCWN)

Tel: 0207 922 7976

e-mail Cecilia.tsang@carersuk.org

Carers UK 32-36 Loman Street, London SE1 0EE www.carersuk.org

SLEH (Specialist Library for Ethnicity & Health):

www.library.nhs.uk/ethnicity

Aims to make accessible all the best currently available electronic evidence relating to health care for minority ethnic groups in Britain

SPRU (Social Policy Research Unit) :

The Social Policy Research Unit at the University of York has an international reputation for excellence in research in social policy, especially health and social care, poverty, social security and social work. Its published research includes studies of health, poverty and carer needs. (<https://www.york.ac.uk/inst/spru/research/summs/DHPcarers.html>)

PRIAE

PRIAE (Policy Research Institute on Ageing & Ethnicity) is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic (BME) elders in the UK and across Europe. The Institute aims to influence national and European policy and increase and encourage good practice in work with BME elders.

31-32 Park Row

Leeds LS1 5JD

0113 285 5990

www.priae.org

The Race Equality Foundation

Promotes race equality in social support and social care. Disseminates good practice through training, conferences and useful briefing papers

www.raceequalityfoundation.org.uk

Equality and Human Rights Commission

Has taken over responsibility from the Commission for Racial Equality (CRE), the Disability Rights Commission (DRC) and the Equal Opportunities Commission (EOC) for promoting racial, disability and sex equality in Britain. Defines and promotes best practice and has guides to download, as well as statutory codes of practice.

<http://www.equalityhumanrights.com>

HARP - Health for asylum seekers and refugees portal

Has resources for working with asylum seekers and refugees. Also provides basic information about different cultures to facilitate culturally sensitive practice

<http://www.harpweb.org.uk/>

Ethnicity Training Network (ETN)

The Ethnicity Training Network has been created to help change the way that people think and work in health and social care services in order to meet the needs of people from minority ethnic and faith communities who have learning disabilities.

<http://www.etn.leeds.ac.uk/>

DipEx / Health Talk Online

A website featuring the experiences of carers of people with mental health problems in minority ethnic communities will be available 'live' on www.healthtalkonline.org (formerly www.dipex.org) in May 2008. The HealthTalk Online collection is an online support and information resource containing people's experiences of health and illness, and is illustrated with extensive video and audio clips. HealthTalk Online research is used widely for training health and other professionals.

www.healthtalkonline.org

Afterthoughts

I am a wife, mother, nurse, teacher, administrator, cook, cleaner, decorator, a great inventor and counsellor. I also am a gardener, personnel trainer, designer, chauffeur, personal shopper (and also budget-keeper), a PA/ receptionist, launderer and travel agent. 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 child)

Coming together was a beginning
Keeping together is progress
And working together is success

As one flock we are gathered together
As one family we dwell together
As one body we are joined together
As one household we are built together
As one kingdom we are to share together
As one hierarchy we are raised up together

Talitha Grant-Higgins (Carer, former Chair NBCCWN NorthWest)