CHALLENGING THE MYTH
“They look after their own”
Black and Minority Ethnic (BME) Carers

The Executive Summary

“They think the Asian community can look after their own”
(A young Carer from the Asian Community)
EXECUTIVE SUMMARY

Introduction

This examination of the extent to which carers services in Wales are accessible to Black and Minority Ethnic (BME) carers is located within the overall 'Caring about Carers - a Strategy for Carers in Wales (Implementation Plan)', a project initiated by the Welsh Assembly Government. Supported also by the Welsh Assembly Government, and carried out within the auspices of AWEMA (All Wales Ethnic Minority Association) as a BME Carers project, this study sets out to explore the needs of BME carers in Wales and the extent to which they felt that their needs were being recognised and addressed by mainstream services.

1. Definition and Scope

1.1 For the purposes of this study, carers were defined as persons who look after family members or friends on a twenty-four hour basis, and provide those cared-for with whole person help and support over a wide range of quality of life facilities.

1.2 Categories of carers whose circumstances were examined in this study included:

(a) young carers i.e. minors within families

(b) partner/spousal carers

(c) parent carers of ill or disabled children

(d) adult carers 18 - 60 years of age, and

(e) carers over 60 years of age
1.3 This examination of BME carers accessibility to Carers Services in Wales focused on the following key variables:

(a) felt needs and access to services as among the carer categories

(b) examples of current good practice and shortfalls

(c) how carer needs were assessed

(d) differences in urban and non-urban environments

1.4 Information contained in this exploratory study was collected using a qualitative approach from a variety of sources as detailed in section 2. It is accepted that the number of carers, cared-for persons, other support organisations and groups is not extensive. However, it should be noted that the views represented derive from a mixed sample of BME carers (mixed by way of ethnicity and carer category), drawn from an area of Wales in which the representation of BME communities is greatest.

1.5 Arising from this exploration of BME carers accessibility to carers services, the overall indicative finding suggests that while some few of the carers interviewed were receiving support, many more were not aware of their entitlement to an assessment of their needs or the existence of support services.

1.6 Hence, following an analysis of the barriers to access and the challenges these pose for providers together with the identification of some areas of good practice, several recommendations for future development are identified, and some illustrative examples listed.
2. **Methodology**

2.1 Three geographical areas were identified as the focus of the study, clustered around the cities of Swansea, Cardiff and Newport.

2.2 Information was obtained from the following sources:

(a) Literature Review: a search of UK material, with particular attention to any local studies

(b) Local Authority providers and other statutory organisations to establish how BME carers were identified, what services were available and how information was disseminated

(c) Voluntary Sector and Private Sector Providers, comprising both BME organisations and others supporting BME carers

(d) Community organisations and groups, not necessarily carer-focused, but with well-established community links

(e) Direct discussions with BME carers, either by way of structured interviews or specially convened focus groups

2.3 Some 43 carers were interviewed altogether, with 8 in Swansea; 29 in Cardiff and 6 in Newport. In category terms, 7 were young carers; 8 were partner/spousal carers; 15 were parent carers; 1 parent/partner carer; 8 were other adult carers (18 - 60 group) and 4 carers over 60. Seven carers interviewed were below the age of 18; fifteen were aged between 26 and 40, seventeen between 41 and 60 and four over 60.

2.4 Two focus groups were held directly with carers, one in Cardiff and another in Newport. Thirteen people who attended the focus group in Cardiff were from the Somali community, of those 4 were carers, and the other attendees were elderly and children being cared for. In Newport, four young carers attended the group with their group leader.

2.5 Responses were received from 22 local authorities. Participation from 12 voluntary sector providers, 4 black-led, and 8 other-led but making provision for BME accessibility, was also secured. Finally, contact was made with 14 community groups and organisations, and their views recorded.
3. Findings

A. Literature Search

3.1 A literature search was conducted at three levels: a wider UK search; studies completed in Wales; reports of local community consultations and smaller-scale studies.

3.2 Part of the literature review considered the historical development of ‘care’ as a concept. More particularly, how care came to be perceived as a systematic set of activities attracting attention as a constituent feature of social policy, the desirability and regulation of which came to be enshrined in legislation such as the Carers (Recognition and Services) Act 1995, supplemented by the Carers and Disabled Children Act 2000.

3.3 Commentary of the modification of carer services to meet the requirements of the Race Relations (Amendment) Act 2000 was also considered. These included identification of accessibility features developed predating the Amendment. Here, the UK-wide review on provision for BME carers in terms of availability of information, completion of assessments and service accessibility broadly substantiates the findings of this exploratory study.

3.4 Evidence gleaned from local studies carried out mainly in the health and housing sectors also mirrors the findings of this study, particularly in relation to accessing culturally-appropriate and language-matched information and services. The lack of investigation into access of support by carers in non-urban areas was also highlighted.

B. Local Authority Commentary

3.5 Local Authorities’ responses included information on their procedures for monitoring, dissemination of information, and assessment of BME carers. Examples provided of good practice and shortfalls offered little evidence in most areas of the availability of specific support services. However, all local authorities were aware of the need to include BME carers in their service planning.

3.6 Most suggested that carer monitoring generally was not a feature of service; hence their inability to reveal ethnic monitoring data. But, fieldwork managers and team members, who are in a position to monitor access and support carers offered the view that only a small number of referrals were
received from BME communities. Some areas were developing better IT systems to underpin monitoring of referrals more generally.

3.7 Remarkably, some social workers were not aware of the Welsh Assembly Government's Carers Strategy and did not offer to complete a carer's assessment as part of their practice generally, and hence were unlikely to undertake this with BME carers.

3.8 It is widely acknowledged that there is a lack of appropriate support for BME carers and there is a clear recognition of the need to address this. Where support for carers is provided by local authorities, it appears predominantly to centre around the service provided for the cared-for person: for example, a cared-for person's attendance at a day centre is interpreted as respite care for the carer.

3.9 Similarly, there is awareness of the need to put in place better means of communication with BME carers and to be more creative in disseminating language-matched information.

3.10 It should be noted that the question of urban and non-urban settings was not considered as an issue in its own right by local authorities. Rather, it was considered that the needs of the locality were met through a process of accommodating the outcome of individual assessments contained in care plans with the resources available.

C. Discussions with Voluntary Sector Providers

3.11 These discussions were undertaken with private and voluntary organisations that represented the views of, or offered support services to, BME carers. The main finding here is of distinct moves in each of the three geographical areas studied towards networking and campaigning on behalf of BME carers.

3.12 There is also evidence of some early work in certain health areas such as diabetes and coronary heart disease, and some initial work in mental health where this has not yet developed, which may provide opportunities in the future for reaching some hitherto hidden carers.

D. Consultations with Community Organisations and Groups

3.13 These contacts were invaluable in identifying BME persons who fitted the accepted social policy definition of carer, but who for a variety of cultural
reasons, did not apply this definition to themselves, or, indeed, were identified as such by the community organisation or group concerned.

3.14 These consultations also revealed the utility of such contacts, both for the dissemination of information and the possible location of future advice shops etc.

E. Outcomes of Focus Groups and Structured Carer Interviews

3.15 Although these qualitative methods were costly in terms of time and interpreter resources, they were the most productive in terms of providing rich information and comment. Further reference is made to some of these findings in Section 4, but the major ones among them are listed as follows:

i) the provision of culturally sensitive care planning and associated carer services, by

ii) workers, who are sensitive to cultural & religious customs and practices in devising care plans and carer services, and who avoid

iii) stereotyping assumptions of BME persons, be they young carers or older carers as 'looking after their own', and

iv) give due regard to the provision of an inclusive, and hence a culturally appropriate and language-matched assessment process of carer and cared-for person

v) recognising at all times that the gate-keeping role of other professionals may also be influenced by their own cultural ethics or racial stereotyping, so,

vi) gain the confidence to give a lead in challenging these assumptions and support the carer and cared-for persons through the process.
4. Barriers to Access

4.1 In common with other carers, the take-up of any carer support services by BME carers is wholly dependent on the services provided for the cared-for person. If these services are not culturally sensitive, the BME carer is most unlikely to take up any carer support services. But the majority of BME carers interviewed were clear that they would welcome support and services if the services offered to the cared-for person were culturally aware and appropriate.

4.2 Only a few BME carers understood the meaning of 'carer assessment'. Some said that they had not been offered an assessment; others that they did not know that they were entitled to it. Yet, others were not sure if they had been assessed, as they were not sure of the procedure.

4.3 Many carers felt that meeting their basic needs e.g. appropriate housing and food, healthcare and social security exacerbated by their caring role (sometimes in a multiple caring situation), was much more of a priority than what they understood to be covered by an assessment of their support needs.

4.4 It was observed, however, that BME carers in receipt of an assessed item of support, valued this; but in some cases, because the support offered was not culturally-sensitive, it was not acceptable and thus terminated (see illustrative examples in Section 7).

4.5 The lack of effective communication with BME carers especially with regard to the availability of language-matched information, including the use of interpreters, is perceived by BME carers as a huge barrier to accessing services.

4.6 Isolation in the community at large through lack of English Language skills. Often, by reason of caring responsibilities, isolation is further exacerbated within the carers’ own cultural communities. Service providers then tend to racially stereotype carers by characterising them as 'looking after their own'; all of which taken together do not contribute towards effective carers' support.
5. Challenges for Service Providers

5.1 Most local authorities agree that they are not satisfactorily addressing issues in respect of BME carer assessment, the accessibility of services to BME carers and the take-up of services by BME carers. Not only are these matters of concern in relation to carer entitlement under specific carer legislation, there is also concern in respect of compliance with the Race Relations (Amendment) Act 2000.

5.2 There is a challenge to the development of appropriate services and their take-up posed by the 'invisibility' of BME carers throughout Wales, given that they are few relative to the majority population. However, Age Concern estimates that BME groups are the fastest ageing group within the population, and it projects that the BME elderly population to have increased ten-fold by 2030, with the greatest part of the increase taking place in the next 15 years.

5.3 Furthermore, research suggests that the notion of caring taking place within the family is fast being eroded through employment migration and cultural integration. Thus, the view of younger generation BME carers in respect of the growing elderly BME population may present a new set of challenges for future service planning and how carer assessments are completed.

5.4 The fact that BME carers themselves are not conversant with 'the system', and therefore do not cause any noise within it by demanding appropriate services, also constitutes a challenge to service providers.

5.5 Not knowing enough about 'the system' and how various parts of our complex service support network hold together, BME carers create a challenge also by their mistrust of professionals who may be perceived to be 'interfering' in their private familial affairs.

5.6 While professionals and community representatives conversant in community languages and cultures may be of value in mediating access to BME carers, there is also a challenge here for the development of quality BME carer support services posed by cultural gate-keeping ethics (see illustrative examples in Section 7).

5.7 There is a challenge to resource allocation in terms of budgets for language-matched communication services (recognising the illiteracy in English and mother-tongue among many female carers in particular); cultural awareness training for front-line workers and strategy developers; and IT developments that permit effective ethnic monitoring.
5.8 Some providers gave examples of developing good practice in the face of these challenges. In the main, these involved either setting up specialist BME oriented projects e.g. the 'barefoot health workers', or supporting BME-led voluntary sector projects e.g. ABCD and AWETU projects, or supporting a specific BME oriented service within a wider project e.g. Multi-Cultural Crossroads.
6. **Some Recommendations.**

6.1 Effective training and/or coaching on cultural diversity and ethnic monitoring to gain the confidence to address carer assessment and professional gate-keeping issues, with a view to assuring quality by avoiding racial stereotyping.

6.2 Consultation with, and where possible joint working with other providers and community advocates to develop trust and acceptance by BME carers.

6.3 Insistence upon non-discriminatory approaches to service planning, care planning and carer assessment.

6.4 Development of a specialist BME Carers Resource Base containing effective practice materials, which may be accessed in areas where numbers are few.

6.5 Creative approaches to the development of language-matched communication facilities.
7. **Some Illustrative examples**

a) A common opening remark among BME Carers was “they think that the community can look after their own”

b) Carers spoke about a dilemma they faced in using interpreters. On the one hand there is a reluctance to share personal information with a person who is not known to them; on the other, many carers do not wish to discuss their affairs with someone they are familiar with in the community (who some also fear may gossip about them). **This underlines the need to work with trained interpreters of whom a professional standard of ethics and service can be both expected and publicised.**

c) When young carers were asked whether the support they received was appropriate to their needs, they took the view that as long as they could trust the people running the service, specific BME oriented services were not necessary for them, but they felt that their elders needed culturally sensitive care: “it is not crucial for us to have a special service, but it is important for older people”

d) Among the things that are important to young carers are: that schools are made aware of their responsibilities; that several media are used to get the message across about entitlement to services and offered in different languages; and, most importantly, that adults take them seriously. They said: “you are expected to do the work of an adult, but not treated that way” and “if you are white, it is easy to come forward”.

e) A community representative said of BME carers: “these people are so distressed and desperate that when anyone takes an interest, they try to get all their issues out”

f) A diverse BME community group advised: that BME carers tended to see ‘caring’ as part of their customary personal or familial role. It was suggested that because BME carers are of this mind-set, they have a poor awareness of available services; do not know how to request support for the cared-for person; do not access carers’ services; find that there is little information available about relevant services at the venues where they are likely to visit; and use mainstream services only as a last resort, usually after some crisis point is reached.

g) Among the comments parent carers offered were: “if it wasn’t for the project worker speaking our language, we wouldn’t be able to get anything
and wouldn’t know where to start.” Another said in support of a one-stop-shop “knowing where to contact someone who is able to advocate or fill in forms or read letters.”

h) There was strong support for services to be needs-led, not service-led: “service providers should assess the needs of individuals and then commission services to fit round these.” Many carers spoke of their most deeply felt needs as around housing, financial benefits and access to basic health services.

i) One carer summed up on access thus: “it is very difficult to get information about available service. The system is very confusing, even for someone like me who has no language or literacy barriers.”

j) Occasional reference was made to the gate-keeping function exercised by some General Practitioners from BME communities. This perpetuates the view that “they look after their own”, supporting cultural barriers and the gender position in certain cultures, and leading these GPs to make an assumption that their patients do not wish to access support.

k) Again carers spoke of their dilemma: to remain with a GP who speaks their language and understands their culture but who reinforces cultural barriers to access, or to change GP and try their life-chances with one who is familiar with service provision, but not minded to provide culturally and linguistically appropriate services? In interviews carers stated that they trust health professionals who reflect their language and culture, but were at the same time suspicious about the service they were getting, and felt also that professionals outside their culture would cater less to their needs.

l) BME carers who are receiving support in the present service provision feel they have no choice about what they receive: they either have to accept what is offered, or go without. One carer stopped meals-on-wheels for the cared-for person because the meals provided could not include halal meat. Another carer, unusually in this study receiving a carer’s item of service, terminated the allocated two hours a week, because this could not be provided on Fridays to enable a much-longed for visit to the mosque.
m) However there was evidence of some support, which was culturally sensitive and much appreciated, offered by BME led voluntary sector agencies.

n) Most BME carers would welcome support provided it was culturally and linguistically appropriate. All would certainly welcome much more publicity about services in venues which they frequent (especially GP surgeries and food shops) and community representatives with the capacity to provide informal and formal sign-posting services.

o) The services provided by BME carers “looking after their own” are valuable, and felt by the carers to be valuable; but it is felt also that its value should not be taken for granted and used as a means by which mainstream support is denied.
8. Postscript

A Directory of Contacts and a Good Practice Guide accompanies this Executive Summary.

All documents are available from:

Carers Team
Social Care Policy
Welsh Assembly Government
Cathays Park
Cardiff
CF3 10NQ

The documents can also be found on the Carers pages of the Welsh Assembly Government’s website at the following address:

www.wales.gov.uk/subisocialpolicy