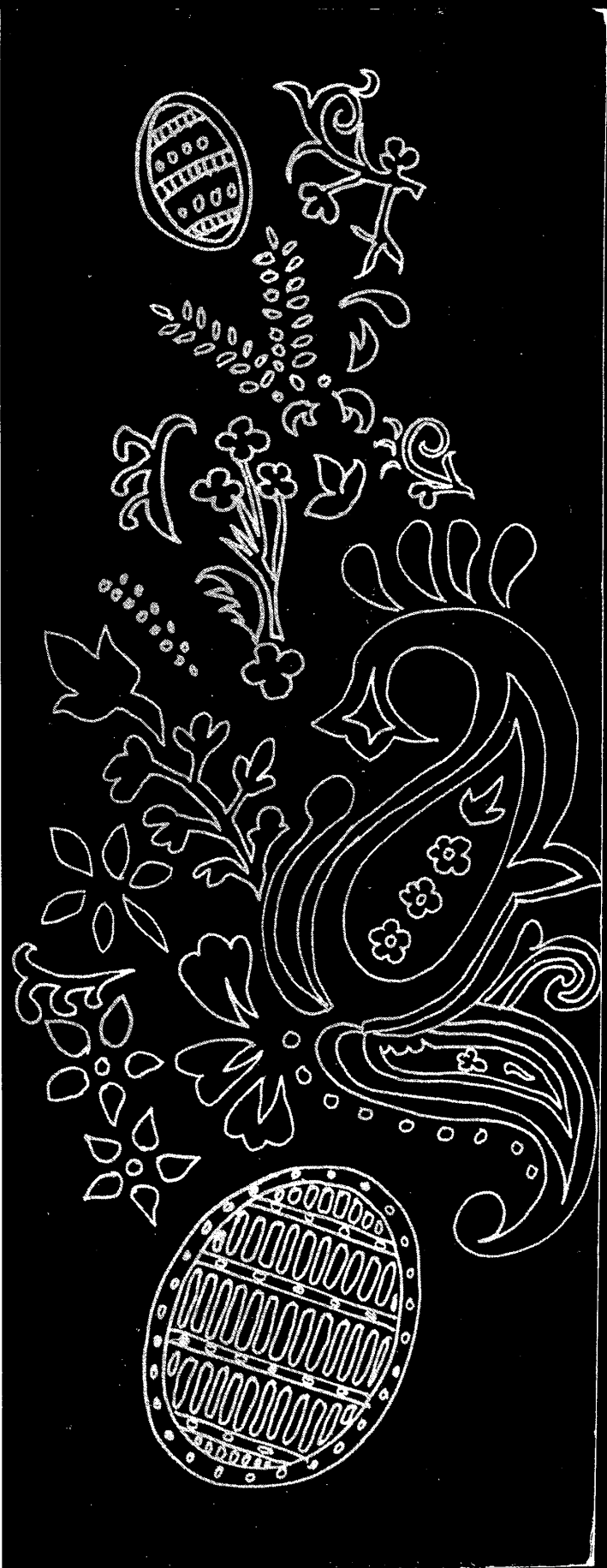
King's Fund

Improving Support for Black Carers

A source-book of information, ideas and service initiatives

Lydia Yee



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Introduction

A key objective of the NHS and Community Care Act 1990 is to 'ensure that service providers make practical support for carers a high priority',[1] in recognition of the fact that 'the great bulk of community care is provided by family, friends and neighbours'.[2] Although this implicitly includes Black carers, support for them remains at the sidelines of community care and will remain so unless there is greater recognition of their specific needs and greater determination to include them in service development initiatives.

Black carers face difficulties in gaining equal access to support services either because they are unaware of available services or find that the services available do not meet their particular needs. This lack of access to support services and the low take-up of services are precisely why working with Black carers is important. The inaccurate assumption that 'they prefer to look after their own' has to be challenged by those with responsibility for developing services because this is often used to justify inadequate provision or low take-up. Black carers also contribute to community care, for which they must be recognised. Much work around Britain is being undertaken for and with Black carers. Workers are seeking ways, often with the support of Black carers themselves, to make their services more sensitive to the needs of Black carers.

This book is an attempt to chart progress in the development of support for Black carers around the country and the factors which can inhibit this process, including racism; lack of joint work between health and social services and voluntary organisations; not taking the issue of Black carers seriously; and competition between Black organisations for funding priorities. This book also acknowledges the many Black carers' initiatives existing in different parts of Britain and considers lessons learned which will help others interested in developing services for Black carers. It draws on the work of the King's Fund Development Centre which has taken a lead role in developing support for Black carers through its service development initiatives and publications. It also draws on the achievements of other organisations throughout Britain, many of which have shared information and ideas through the National Black Carers Forum convened by the King's Fund Development Centre.

There are now many others genuinely wanting to improve support for Black carers, and with this comes the demand for answers to three fundamental questions:

- Why is it important for me to support Black carers?
- How can I support Black carers in my local area?
- What are other people doing to support Black carers and what can I learn from them?

This book tries to answer these questions. It also explores some of the dilemmas that exist when developing services for Black carers:

- Is it enough to tackle cultural issues when improving support for Black carers or should racism be challenged?
- When should services be separate or integrated for Black carers?
- Does the voluntary sector equal marginalisation for Black carers?

There are no easy answers to these questions but everyone engaged in service development will need to explore these issues.

Using this publication

This book is intended to be a point of reference primarily for workers (Black and white) in both statutory and voluntary agencies. It will be especially useful for those workers with responsibility for developing services in the light of recent community care legislation. Voluntary organisations may find it a useful guide to their work with statutory agencies in encouraging them to support Black carers. Workers in health services and local authorities will be able to learn from the lessons of colleagues in other areas, and the broad practical guidance offered could be applied in their own local areas. Readers may already be working in many of the ways we suggest, and contact details are provided for them to liaise with colleagues in other areas to share successes and pitfalls in working to improve support for Black carers.

This publication does not set out to offer detailed step-by-step advice nor can it claim to be a comprehensive compendium of everything that has been and should be done to support Black carers. It will highlight many initiatives around Britain improving support for Black carers and the people who are already playing their part to nudge Black carers' issues up the policy and practice agenda.

A note on terminology

Black refers to people from minority ethnic communities in Britain who may be disadvantaged because of their skin colour or their racial, cultural and religious backgrounds. We are aware that there is no single accepted definition and that there are people who do not identify themselves as 'Black' but who share a common experience of racism.

Carer is used to describe anyone whose life is restricted by undertaking caring tasks because of a relative's or friend's disability or illness. Carers are often family members, friends or neighbours, and their caring responsibilities include regularly helping another person with everyday activities, such as shopping, cooking, getting around the house or local community or with personal tasks, such as washing and dressing. A carer may live in the same house as the person cared for or may live separately. A carer may be providing either full-time care or care only at certain times.

Racism. We all hold beliefs that are prejudiced about people whom we see as being different because of their racial groups or skin colour, but 'racism' is attributed to those who have the power to turn the prejudice into acts of discrimination or unfair treatment. For instance, this may occur when service providers in a day centre only offer English food and ignore the preference of Black clients, or base decisions on racist assumptions and stereotypes, such as the idea that Black families 'look after their own' and therefore do not require support.

Refugee. This is a legal term which has a specific meaning. For someone to be recognised as having 'refugee status', they must have left their own country or be unable to return to it because of a 'well-founded fear of persecution owing to race, religion, nationality, membership of a particular social group or political grouping'.[3] Refugees are entitled to all public services, such as education, housing, health and social services in the same way as anyone else living in Britain. They are also protected from being deported. The main groups of people who have sought asylum in Britain during the 1980s and early 1990s are the Vietnamese, Eritreans, Somalis, Ethiopians, Ugandans, Ghanaians, Sri-Lankans, Tamils, Curds and, more recently, people from Bosnia.

Chapter 1

Who are Black carers and what do we know about them?

Black populations in Britain: a thumbnail sketch

The 1991 census was the first to record information on ethnic origin, which provided valuable data for studying Britain's multi-racial communities previously classified under country of origin rather than ethnic origin. According to the annual Labour Force Survey, about 5 per cent of the total population in Britain are from minority communities.[4] Fifty per cent of these people were born in Britain. People from the Indian sub-continent (India, Pakistan and Bangladesh) are the single largest minority group, with the African-Caribbean community in second place.

According to the 1991 census figures, the highest proportions of Black groups reside in London. Almost 60 per cent of the African Caribbean population live in London and especially in inner London. Half the Bangladeshi community live in inner London, while the Pakistani community live primarily in the West Midlands (20 per cent) and West Yorkshire (18 per cent). Thirty-eight per cent of the Chinese population live in London and, unlike the other Black communities, show no particular concentration elsewhere.[5]

It is difficult to estimate from these figures how many Black carers there are. The most recent General Household Survey figures published in 1990 by the Office of Population Censuses and Surveys indicate that in the general population 15 per cent of people aged 16 and over were caring in 1990, compared with 1 per cent in 1985, suggesting there are now around 6.8 million carers in Britain today. Although women are more likely (17 per cent) to take the main responsibility for looking after someone, the figure for men has increased to 13 per cent. In 1990, 1.5 million adults (6 per cent men and 10 per cent women) were spending 20 hours or more a week caring.[6] A national breakdown of these figures in relation to the Black communities is not available but we know that the Black population in Britain is on the increase. Demographic changes in the next ten years will mean increased caring responsibilities for Black families. As the Black elderly population is growing so there will be a corresponding increase in the number of people requiring care.

As Black people tend not to access statutory services easily, frail and disabled members must be cared for in the communities. There has been much local research conducted recently to bear this out in areas such as Greenwich,[7] Lambeth,[8] Lewisham,[9] Kent,[10] Gloucestershire,[11] and Birmingham.[12] Although based in different parts of Britain, all these reports have one key element in common: the users and carers interviewed, for a variety of reasons which we shall explore in the next section, found it difficult to access services and were often unaware of services available either to them or the people they cared for.

Chapter 2

Issues affecting Black carers

Black carers do not seek out support services and there is therefore a low take-up of services by them. This is not because Black carers have readily available family networks to support caring tasks or because they have different needs from those of white carers. In fact, Black carers share many of the same needs as white carers. They want to be recognised for their role as carers, receiving services which are both appropriate and flexible. All carers want someone to talk to about their caring role, information about available help and regular opportunities to take a break from caring. Poverty, poor housing and unemployment are also factors affecting carers, irrespective of race. It is true that the lack of information about services and the unsuitability of available services are contributing reasons for Black carers not using support services. There is, however, one additional factor that sets Black carers apart and differentiates their life experiences from others – that of racism.

- The racism stereotyping Black families as 'wanting to look after their own' because of the extended family myth. Black families are assumed to be large with a preference for caring without alternative support. This stereotype means that providers do not consider the need to support carers or the people they look after assuming that Black families prefer to do this for themselves. The report published by Medway and Gillingham Race Equality Council[13] refutes this myth, showing that less than half the Black carers interviewed lived within extended families.
- The racism of a colour-blind approach to service delivery, where Black carers are expected to fit into existing services when their needs may require specific responses. The London Borough of Camden published a report in 1990 which stated that 'providing the same service in the light of differing need is not providing an equitable service.'[14] For example, not informing Black carers about available respite services in their mother tongue excludes many of them who do not have English as their first language from this service.
- The racism which continues to see Black carers as immigrants in Britain thus considering their stay in this country as temporary. This damaging view does not accept British-born Black people as permanently resident here and therefore entitled to services. As mentioned earlier, the 1991 census figures show that at least 50 per cent of Britain's Black population today was born in Britain.

Special or specific?

Racism is rarely used to explain why Black carers do not make use of services, although service providers may want to consider this to question the basis on which decisions are made, looking especially at equity in the delivery of services. A popular response to supporting Black carers is often to provide 'special' services which may be appropriate and helpful, although the tendency to describe Black carers' needs as 'special' presents them as a problematic group requiring additional resources from an ever-constricting public pool. 'There has been a tendency for the special needs label to be applied too readily to minority ethnic groups, which tends to consign to minority ethnic groups a deviant status and which marginalises any provision...'[15]

Much support requested by Black carers is *specific* rather than special. For instance, offering a sitting service where staff members speak Punjabi or providing a prayer room for Muslim clients in a day centre is by no means special but certainly a specific response.

Knowledge of services

Services are offered to Black carers on a take-it-or-leave-it basis, resulting in the low take-up of services. Black carers are also discouraged from using the services because they are unaware of available services, the routes to access those services and the information networks within their localities. Research in the Medway and Gillingham areas of Kent in 1992 showed that half the carers were not using services because they did not know they existed (see Table 1).

Table 1 People who did not know about services

Community service	*Proportion not aware of each service*	
	Asian (n=81)	White (n=55)
District nurse	57	14
Nurse auxiliaries	76	32
Chiropody	64	9
Home help	62	1
Meals on wheels	58	0
Social work	44	6
Day care	60	18

Source: Atkin *et al.*[16] Reproduced by permission

Research undertaken in Birmingham and Kent has shown that carers will consider using services once they have been described to them. Out of the 30 carers interviewed in Medway and Gillingham, eleven agreed to consider using respite services in the future with more information provided.

Typically, Black carers tend to use local Black community organisations for support preferring the accessibility and appropriateness of the services provided.

> *I don't understand English. Whenever I receive an English letter or have any problems, I go down the community centre and ask for help.*[17]

Ideally, local Black community organisations should be in a position to offer help to Black carers, but very often they provide a range of services assisting clients with welfare rights advice, dealing with racial harassment cases, immigration and housing problems. Caring is one of the issues clients may raise with community workers but, in the hierarchy of needs, this may not be considered most pressing.

In addition, the term 'carer' is not a familiar one within Black communities. This can be a cause for confusion. If community workers and Black carers themselves are not familiar with the term, it can be difficult for them to communicate with service providers who use this term to identify the people they support.

Suspicion of the State

Sometimes carers, especially those from refugee communities, are mistrustful of the State system and therefore do not use services that may be available. Often they have fled oppressive regimes where they may have suffered violence, torture and intimidation against themselves, their families and friends. Accessing health and social services systems is therefore a major problem for refugee carers. Their history of bad experiences with those in authority does not lead them to contact statutory services as the first port of call for help.

Language and cultural barriers

Difficulty with the English language and cultural barriers create problems such as poor communication with those in statutory agencies, reading local information usually written in English, calling the emergency services, expressing their needs as carers and explaining symptoms to GPs. For example, 70 per cent of first-generation Chinese do not have English as their first language according to the 1985 Home Affairs Committee report on the Chinese

community.[18] The Chinese carers project in Merseyside highlighted that 60 per cent of the people they interviewed did not have English as their first language and admitted that even when help was offered to them, they had difficulties communicating with service providers on their own.

Conclusions

It is, however, not all bad news. Increasingly, Black voluntary organisations and statutory agencies are beginning to recognise the importance of supporting carers in their caring roles. This support is offered in a variety of ways – through the provision of information, support groups and practical services. Much of this work is in the early stages of development but with continued commitment to supporting carers and adequate resources (financial and otherwise), improvement to Black carers' lives will remain a high priority.

Chapter 3

Developing services for Black carers

Getting started

There has been a growing interest to improve support for Black carers – working across different activities in different parts of Britain. Typically, the activities have involved establishing support groups for Black carers; providing services such as respite care; offering information and advice, mainly through publications; undertaking local research studies to ascertain need and service development initiatives to improve mainstream support for Black carers. These approaches to improving support for Black carers require asking important questions at the initial stages of any development programme.

It is easy to adopt a 'knee-jerk' reaction to supporting Black carers because we ought to or because it is fashionable to do so at the moment. These are not good enough reasons. A failure to think through the importance of improving services for Black carers is likely to impair the sound foundation needed for any development work to flourish. Before developing support services for Black carers, it will be important to consider the following key questions.

Why do you want to support Black carers?

Knowing and reaffirming your reasons from the onset will confirm your commitment. It will also encourage others to be involved too.

Who do I need to work with to bring about an improvement in services for Black carers?

Identifying stakeholders (people who will be affected by the work) is important in order for you to call upon their support, to help you access the Black communities, to assist with the planning and resourcing of the work. Choosing the right people to work with at this stage will also ensure that the work programme will be relevant to the carers you want to support and that there will be ownership of the programme during implementation.

What do Black carers want and how can I best deliver the service to them?

Finding out exactly what is important for Black carers will help you to focus on the services you may want to provide or perhaps even to work jointly with other local organisations to support Black carers.

There can be a problem when Black carers' workers are expected to undertake or have expectations of undertaking the work single-handedly. The isolation can be avoided through working with others, keeping abreast of national developments for improving Black carers' support, and making contact with the relevant workers concerned for their support.

A word of warning

The danger with the last two stages is to spend too much time undertaking feasibility work and therefore leaving little time for implementing the programme. This is especially pertinent for work that is funded for one or two years where too much time is spent preparing the groundwork leaving insufficient time for productive outcomes to be achieved.

How do I know that the work for Black carers has been a success?

Consulting carers about their needs and how these can be met will offer the starting point for developing an evaluation programme – establishing the criteria for success with the stakeholders and carers themselves. It is never too early to think of evaluating your work because this will provide a continuing marker against which to measure performance and also to amend work plans if necessary.

Evaluating the work can and should be regularly undertaken by the stakeholders, for example any advisory group and carers themselves asking questions such as: What do we want to achieve? How do we know if we have achieved our goals? What happens if we do not meet them?

How can other people learn from my work?

Sharing with other people the lessons learnt from your work (successes and pitfalls) is also important. It will provide others wanting to develop Black carers' support with useful guidance or will encourage those not yet convinced of the importance of supporting Black carers to rethink their future plans.

Conclusions

Thinking through systematically ways of working with Black carers, who you need to work with and the necessary ingredients to make the project successful at the initial stages of development will ensure strong foundations to the work programme. It will also provide the opportunity to clarify fundamental issues, such as Black carers' involvement and the specific support activities to be provided by the project.

Chapter 4

Service development for Black carers

Supporting Black carers

We have already seen that Black carers have varied needs, many similar to those of white carers and others requiring specific responses. Carers groups, voluntary organisations and local authorities have led in the development of Black carers' initiatives. The following are examples of the different approaches taken to improve Black carers' support around the country. Key action points have been drawn together from the lessons learnt, and these are offered as tips you may wish to consider rather than as the definitive answers to improving Black carers' support. In fact, there is no one best way of undertaking any development work. Several strategies are often required to ensure that Black carers' needs are met.

A contact list of the organisations working with Black carers mentioned below is provided in Appendix 1.

Research into Black carers' issues (to find out more before taking action)

Undertaking research to highlight need and to understand about carers' experiences of the service system can be very valuable, but there is the danger that research can become a substitute for implementing support for Black carers. The positive reason for conducting research before any action is taken would be to make sure that what is being offered reflects what carers want. Endless research studies all confirming findings can eat into valuable development time, and it is therefore important to use existing information from research studies undertaken both nationally and locally which can be of help.

- Medway and Gillingham Race Equality Council produced a report in 1993 highlighting the needs of Black elderly people and their carers in the Medway towns.
- Hammersmith and Fulham Caring for Carers Association have produced a report on the needs of Black carers with recommendations for meeting them.
- Gloucestershire Black Carers Forum have produced a report arising from a conference for Black carers held in April 1994.

- Camden Council produced a report in 1991 highlighting the needs of women carers whose first language is not English, with a comprehensive list of recommendations.
- Lewisham Council produced a report in 1990 highlighting the needs of carers of elderly and disabled people in the local area.
- The Nuffield Community Care Studies Unit at Leicester University started a two-year research project in April 1995 developing guidelines for primary health care teams in their work with carers from Asian communities.
- Research has been under way in Lambeth to identify the respite care needs of carers. Black carers will feature prominently and recommendations for changes in service provision will be made.

KEY ACTION POINTS

Question the need to carry out research work. It may be important to invest in evidence of Black carers' needs locally but existing research can be used to aid this work. For research undertaken as part of a development project, it is important to place a time limit on the research task so that it does not overtake other developmental activities.

Black carers complain about researchers always expecting them to share information about their lives and experiences, offering little else in return. It is important to decide from the onset what you are able to offer Black carers. For example, providing a summary of your research findings presented in a format that is accessible for them.

Recommendations for change arising from research can sometimes be vague and unrealistic. For example, 'local Black carers' needs must be recognised and sufficient training must be provided.' The enormity of this task can be overwhelming and make it difficult to implement. Setting specific and achievable goals will convey to those involved what they can expect from the work programme and maintain commitment to improving services.

Consultation with Black carers (to find out what carers want, what they think is important)

Local authorities have a duty to consult with local communities when drawing up their community care plans. Consultation with Black carers about either local community care plans or specific services has tended to involve talking to Black organisations or with so-called leaders of Black communities. Black carers themselves are bypassed. Failure to canvas carers'

views can lead to unsuitable services. However, some attempts have been made to reverse this trend in seeking Black carers' views and going to them directly.

- Oxfordshire Carers Forum held a consultative meeting with 50 Black carers about the services they needed and how this should best be delivered. Respite care was top of the list and ex-carers present suggested being trained to provide this service for their own communities. They thought this would encourage Black carers to take up respite services if offered. The Forum is working in conjunction with the African-Caribbean Association in Oxford on a proposal to implement this idea.
- Birmingham Social Services Department has consulted Chinese, Asian and African-Caribbean carers over a period of time about their community care plans. Lessons from these consultation exercises have been drawn up in a series of reports.
- The Carers Forum in the Borough of Redbridge has held a series of three open meetings for Black carers locally. As a result, a group of volunteers have agreed to feed Black carers' views into the Redbridge Carers Working Party to influence policy decisions.
- Northamptonshire Social Services Department has produced a comprehensive carers' strategy for the county. They have identified the 'invisibility' of Black carers locally and as a result, Black carers will be consulted about the strategy and how it could best meet their needs. A multi-disciplinary working group of Black community workers and health and social services colleagues has been set up to consult Black carers.

Key action points

When consulting Black carers, meetings need to be organised at venues familiar to them and where they feel safe. This will also mean tailoring meetings to suit specific needs. For instance, large open meetings may be inhibiting and daunting for Black carers.

Invitation by word of mouth rather than by blanket advertising is vital. This also offers the opportunity to explain the term 'carer', which many do not identify with. Before a recent consultative meeting in Wandsworth, Black carers were visited in their own homes and informed about the consultation process and what they should expect from the exercise. They were helped to ask questions and to offer their views through Black workers.

Talking about their caring role and expectations is unusual for Black carers and therefore may be difficult for them. Consideration should be given to having trained staff who may be able to deal with carers' feelings at these meetings so that carers do not leave feeling guilty and distraught.

Producing information for Black carers

Black carers often cite the provision of information about available services as a key to supporting them. They want to know what services are available to assist with the caring role, how to access these services and whom they should contact for help. There are now many publications around for Black carers signposting them to services and offering advice on how to approach their local service providers for support.

- The King's Fund has published a series of booklets and videos aimed at African-Caribbean, Asian and Chinese carers.
- Tower Hamlets Bengali Carers group is producing a video for local carers.
- Camden Crossroads is publishing translated leaflets about the services they offer.
- Leeds Social Services Department is producing leaflets in different community languages offering information about locally available services.
- Gloucestershire Black Carers Forum has hosted information days as a means of getting information to Black carers. This has led the Forum to produce an information pack for Black carers locally.
- The Carers Advocacy Project in Wellingborough offers advice to Black carers and liaises on their behalf with local and health authorities when needed.

KEY ACTION POINTS

Consult carers about their information needs and the best ways of producing information.

Draw up an information strategy showing the types of materials you want to publish (e.g. videos, books, leaflets, tapes) and decide on how and to whom these will be disseminated.

It may be appropriate to select a suitable Black community organisation or Black writer through a tendering process, to produce the information for you. This was the approach adopted by the King's Fund Development Centre, who did not presume to have the expertise within the organisation to produce information aimed at Black carers.

Set up a steering group to assist with the planning of information materials and the editing of drafts and to enlist the support of others who may already have experience of producing information for Black communities.

KEY ACTION POINTS

Pilot draft materials with Black carers in order to ensure the content and presentation will be relevant and helpful.

Contact the local council of voluntary service (CVS) or perhaps another umbrella voluntary organisation, the local authority or health authority to obtain a list of translators they would recommend if you do not know of any.

Make sure to seek and take up references for translators to check whether previous work they produced was suitable. Literal translations of English documents are of no use to carers because some words in English do not translate well and can make the information contained in the document inaccurate.

Spend time on your dissemination strategy to avoid having stacks of publications in cupboards, unread. Plan through who should receive the information, the most appropriate means of getting information to them (e.g. in the post, at an open meeting, through community workers, temples, churches, local radio, libraries, local GPs) and signal whom the carers can contact for further details. It is also important to consider who else can help you to distribute the information in order to save time and money.

Ensure that staff members are trained to provide appropriate initial information to Black carers.

Think through how you would cope with the increased demand for further information initially after the publication is launched.

Monitor the take-up of information to provide you with a clear picture of how useful or otherwise Black carers found the information. This can act as a guide in the development of further information in the future.

Review your information strategy regularly to ensure that you are meeting the needs of local Black carers.

In setting up information days for Black carers, ensure that the venue is accessible to them and that they are able to attend. Some Black carers are not familiar with such events and may feel uncomfortable about attending on their own. It may be helpful to offer to pick them up individually from their homes to encourage them to attend. When an information day for Black carers was held in Dudley, workers there visited carers' homes prior to the event explaining the purpose of the day and how it could be of use to them. This boosted the carers' confidence to attend.

Black carers' support groups

Support groups for Black carers are growing around the country. They provide a source of comfort, respite and information for carers. Many of the Black carers' support groups offer services, such as counselling, information exchange and training. They are supported by local voluntary organisations (e.g. Age Concern, Carers National Association), Black community organisations, or local authorities, mostly on minimal resources, and are run by one or two people.

- Based in Liverpool, the Merseyside Chinese Community Development Association have set up a carers group for people who look after relatives with mental illness. Chinese-speaking social workers and psychiatrists were invited to offer the carers more information about their relatives' illness and how to cope with it. Having the information in their own language helped the carers to understand more about mental illness and what help was available for them.
- The Annie Wood Resource Centre in Birmingham has been running a regular support group for Black carers since 1989. Some of the developments to date have been to set up a bereavement group, organise annual holiday breaks and enable people to share their experiences of caring in their mother tongue.
- Sahara Project in Greenwich hold regular support group meetings for Asian carers where they are able to talk about their own needs and to gain information about benefit entitlement and local services.
- The Chapeltown Carers Group in Leeds also run regular Black carers' support group meetings.

KEY ACTION POINTS

Do not assume that all Black carers either do or do not want to join support groups before consulting them. Some carers find a lot of support from joining carers groups, while others want to participate in activities that take them away from caring.

Agree with the carers who will run the group and have responsibility for organising meetings. If responsibility for the group is not agreed early on, this could cause confusion and uncertainty among members.

It is important to agree with the carers themselves whether the group should be open to everyone who is or has been a carer or only to those caring for someone with a particular illness or disability.

The venue is also an important consideration for Black carers. They would not want to attend a support group meeting held in an area well known for racist attacks, for instance. Support groups held in areas frequented by the carers themselves are ideal (e.g. community centres often used by Black communities, mosques, temples and churches).

Meetings should be held at times when people are able to attend. This is especially true for those carers who work. Some of the Chinese carers in Liverpool tended to work long hours in their catering businesses and had difficulty attending meetings. Therefore meetings had to be planned carefully to include as many carers as possible.

Carers may feel guilty at joining the group meetings and leaving their relatives at home. In order to encourage carers to join the group, the Liverpool Chinese carers group organised a crèche, Chinese video and other entertainment so that the carers group meetings could take place without interruption.

Programmes for the group meetings should be determined by the carers themselves. This will ensure their commitment to the group and will enable them to take responsibility for making the best use of their time together.

Service initiatives

Respite care

Respite care ranks as the top support requested by carers, including Black carers. It may include night sitting, home-sitting service, day care, temporary placement in hospital or residential homes. Black carers complain about the lack of trust in leaving their relative with a stranger. This is exacerbated by the shortage of care attendants from the same cultural background who would be able to communicate with the person being cared for and understand how to cater for their specific needs. Existing respite schemes are also not flexible enough to cater for Black carers' specific needs, such as attending weddings which tend not to be one-day events or taking long trips abroad to visit other relatives. As a result, some respite schemes have been established to meet the specific needs of Black carers.

- Alzheimer's Concern Ealing run a weekend respite scheme in a local day hospital which has allocated a specified number of places for Asian people. There are staff members who speak the different Asian languages, and currently two-thirds of the carers using the services are Asian.
- Mencap Leicester have created a sitting service for Asian carers. This arose from a review indicating that Black carers were not taking up their services. There are currently about 20 Asian volunteers offering respite support to about 30 families. Mencap Leicester is currently focusing its work to provide a similar scheme to the African-Caribbean community.
- Age Concern Wandsworth offer a befriending service for Asian carers, enabling them to go out of the home for a short period of time. The carers were initially reluctant to leave their relatives with a stranger but, as trust in the volunteers has grown, they now find this a useful service.
- The Time Out Respite Care Project in Nottingham works in partnership with the district health authority and social services department to provide respite care to African-Caribbean carers. There are currently five carer support workers in post, providing help to 45 carers and offering a range of services from home-sitting service, night sitting and advocacy. A future aim of the project is to encourage the statutory agencies to purchase respite services from them for their African-Caribbean carers.

KEY ACTION POINTS

Respite care services sensitive to the needs of Black carers must be flexible. It may be necessary to provide longer respite hours/time for families who have commitments such as going on long journeys abroad.

It is important to send the same volunteer to a carer's home in order for them to build up a relationship with each other, including the person being cared for. Initially, Asian carers in Wandsworth were reluctant to accept the respite support offered and, when they did, they were reluctant to leave their relative at home alone with the volunteer. Trust was built up over a period of about three months and carers are now confident about going out.

The lengthy process of recruiting, training and matching volunteers and paid staff to families should not be a deterrent to providing this service. The benefits to Black carers who do not readily access respite services are enormous.

For Black carers whose relatives go outside the home for respite, it is also important to employ workers from the same cultural background to look after them. Making the environment less alien with acceptable food, with clients from their cultural background and with staff who understand their needs will encourage Black carers to make more use of the service.

Home care

The London Boroughs of Lewisham (in 1990) and Camden (in 1989) reviewed their home help services and found that they were not delivering an adequate service to Black communities. There was a low take-up of services from these communities in spite of sizeable Black populations in both these boroughs. This scenario is typical of many authorities, and local voluntary organisations are beginning to take the lead in providing home care support to Black carers and those they care for.

- The London Chinese Health Resource Centre's Carers Project and Disability Support Scheme recruits and trains Chinese-speaking volunteers as care assistants. The services provided include befriending, interpreting, advocacy and general help with information. Carers hear of this service mainly by word of mouth and request care assistants once they know of their eligibility for the service. In the words of the carers' worker, 'It breaks down the myth that the Chinese are private people and do not want help.'

- Camden Crossroads will be employing two care attendants to work with Bengali and Greek carers specifically, although not exclusively. They will be trained to provide home care services, such as personal care, first aid, lifting and handling. A pool of Black sessional workers will also be established to support local Black carers when required. They will be expected to undergo the Crossroads training programme to provide a high-quality service to Black carers.
- Alzheimer's Concern Ealing run a call and care service where help such as bathing is offered. Trained African-Caribbean and Asian care attendant staff offer a service to members of those communities. A quarter of carers using the service are Black, and having staff from different communities must also account for the popularity of this service.

KEY ACTION POINTS

As with respite services, carers will want to be confident that the care attendants they have to support them are well trained, able to communicate with the person cared for and therefore cater for their needs. Black carers will then be encouraged to use the service.

Camden Crossroads have reported that, on occasion, some Black carers have specifically requested not to have care attendants from their own communities because of the perceived stigma of their situation. For instance, a carer may not want another member from her or his community to know that their relative has a mental illness. This should be respected and has implications for the training of all home helpers. The training should include working with Black carers and users with details of different cultures, racism and its impact on Black people's lives and the effects of stereotyping.

It is important to include carers in the planning of any home care service to offer them control over a service they will be recipients of. This would also encourage them to make use of the home care service. As a key principle, home care should complement rather than compete with the caring role.

Where Black carers are anxious about strange people coming into the house, this is not likely to be relieved by having a number of different workers. Informing carers about their home helper or care attendant beforehand and telling them in advance of any changes contribute towards a good-quality service that carers will want to use.

Strategic approaches to carers' support

Carers' service development at the King's Fund meant working in different localities around Britain to improve direct services offered by health and local authorities. Organisations will use different terms for this, such as project working or development work. A common thread running throughout is to make sure that the services provided by local and health authorities meet carers' needs.

Efforts at the King's Fund to stimulate and support services began in 1990 with projects in Nottingham, Oxford, Yorkshire and Doncaster. Ensuring that these projects reflected the needs of Black carers was integral in the working contract, although it was often difficult to make this happen during the life of the development project because of competing priorities. Therefore in 1992 it was agreed to have a specific service development initiative aimed to improve support for Black carers and users.

A two-year project was established in the London Borough of Lewisham to improve mainstream mental health services for Black users and their carers. The project set out to work with local voluntary organisations who would offer advice and expertise based on their experience of working with mental health service users and their carers. Key outcomes of the project have included: raising staff awareness of Black carers' issues; involving carers in care plans before their relatives were discharged from the wards; producing information about mental illness for Black carers available on the wards; and setting up a Black carers forum. A final report has been published.

Another King's Fund service development initiative has been established in Gloucester through the Carers Impact Project which aims to involve carers in the planning, management and delivery of services. This project is current and its intended outcomes are to provide Black carers with better information so that they are able to have a say in how services are run for them.

Working with mainstream agencies to improve support for Black carers offers the opportunity to change staff practice (e.g. Black carers receiving assessments in their own first language).

KEY ACTION POINTS

Consult with local Black communities about the feasibility of such a project in the locality. Be as clear as you can at this stage about what the project can offer the various communities so that people will know what to expect of the work.

Identify people from the Black communities, from voluntary organisations, churches, temples, local authorities and health agencies to assist with the planning of the work. It may help to set up an advisory group who meet regularly to guide the development.

Including senior managers early on in the work programme will ensure long-term commitment to the project work and integration of lessons learnt into wider departmental work. This is particularly pertinent for Black service development initiatives where interest in race work can be lost in the light of competing priorities. It is also more difficult to initiate change among practitioners with entrenched views and practices in the absence of support from senior management.

From the beginning, criteria for success and expected outcomes should be established. Not identifying what you want to achieve at an early stage will demotivate people within the project, if nothing seems to be achieved, and offers no direction to those having to implement the plans.

While it is important to undertake a feasibility study to identify local Black carers' needs, there is a danger of spending a lot of development time on this, delaying the implementation phase of work.

Be clear about whom the project is aimed to serve. If it is to improve support for all Black carers, ensure that everyone is clear about the terminology used. The term 'Black' to some people means African-Caribbean and therefore other communities may not see the significance of your work to them. Either consult with carers on a suitable term to use or inform people through publicity materials about the definition used to avoid confusion and bad feelings.

Consulting with Black carers on the feasibility of the development idea is not an end in itself. At regular intervals (at least six-monthly) it will be useful to inform people either through local press, leaflets or local radio programmes about progress made in the project work to maintain interest and to keep the issue of Black carers on the local agenda.

Chapter 5

Dilemmas in developing support for Black carers

In the process of developing better support for Black carers, several key issues keep recurring. These are difficulties and dilemmas which can arise on a day-to-day basis. They need to be debated openly or they may inhibit service development efforts. Below, three experienced development workers discuss the following dilemmas.

- Should racism be challenged or is it adequate to tackle cultural issues when improving support for Black carers?
- Should services for Black carers be separate or integrated?
- Does voluntary sector equal marginalisation for Black carers?

Readers can contribute to the debate on these issues through the London Black Carers Forum and the Midlands Black Carers Forum. (See Appendix 2.)

Should racism be challenged or is it adequate to tackle cultural issues when improving support for Black carers?

Jenny Alphonse, Manager, Camden Crossroads Scheme

It has become increasingly apparent that statutory organisations find it far more palatable to use variations on a theme of the term 'ethnically sensitive'. Challenging the effects of racism, or even stating the term in public, seems to provoke waves of uncomfortable shifting in seats and sideways glances. Try using words like 'cultural', 'ethnic' and 'difference' and you will see people relaxing visibly – perhaps just a slight crossing of the leg and a cursory nod of approval.

This is typified in debates about supporting Black carers. Much fuss is made about the provision of 'ethnically sensitive' food, good hair and skin care. There is no talk, however, of challenging institutional racism in order to improve the lives of Black carers. To do so would mean working on both fronts (cultural and racism) or else risk constraining our work and not getting very far in supporting Black carers. Black carers' projects would continue to receive 'soft' money on a short-term basis where any changes made would be difficult to sustain.

Why has it become more comfortable to side-step on the fundamental issue of institutionalised racism? If it were not for the fact that racism is still alive and deftly woven into the very fabric of most organisational structures, we would not be seeking ways – whether they be considered 'soft' options or not – to address the serious effects racism has on the lives of Black carers.

There is a broad acceptance of the importance of being sensitive to cultural needs. Where does this leave Black carers? How will they be supported within an intrinsically racist framework of service delivery? For example, the argument for separate needs assessments for carers has yet to be fully embraced by a number of local authorities. Challenging racism has never been easy, and history has shown us that results take a long time to materialise. It is no wonder that the cultural options for Black carers seem more attractive.

The experience of some workers appointed to work with Black carers can often be a mirror image of the effects of institutionalised racism in practice – that is one of isolation, poor management, lack of knowledge, support, commitment and short-term funding. This has the distinct flavour of raising expectations that are not possible to meet with limited support. Part of the problem lies with the way in which organisational structures perceive and prescribe needs and services respectively. Once again, there appears to be a problem of letting go of a paternalistic, prescriptive approach. After all, can Black people in their communities really manage themselves, identify their own needs – which may not fit into a white perspective of what a carer is – and seek to have these needs met appropriately?

Black people, either as workers within statutory and voluntary organisations or as recipients of services, may be caught up in the whole debate around facing the realities of care in the community. There could still be a way for Black carers, their communities, their advocates and supporters to continue to fight for the ever-diminishing 'cake'.

There is a great deal of experience and growing expertise among people working at grass-roots level. They need to network and to capitalise on this knowledge, helping Black carers to challenge a system which is prepared to see the importance of cultural sensitivity but seems to stop short of acknowledging how racism in practice can work against the long-term successful delivery of support to Black carers.

Should services for Black carers be separate or integrated?

Judi Ann Dumont, Ealing User/Carer Project

It cannot be ignored that there is a low take-up of mainstream services by Black people. Or that some services are steeped in racist and prejudicial practices. There is an inbred fear of difference and of change, and only a few services have dealt with the problem.

Surely, the lack of up-take does not mean that Black people do not need services. Are there any answers? Some would say we need to have 'Black only' services run by Black people for Black people. Others would contend that this would be a big mistake and would assert that we need appropriate services that meet where possible all needs, and when they cannot be met, contracts with Black-only services can meet those specific needs.

Let us first look at the reasons for separately run services for Black people and then consider why this may not be the complete answer and what else needs to be done by mainstream providers and purchasers.

Potential advantages for Black carers

- The provision to meet appropriate language needs. The ease of speaking to someone directly rather than through an interpreter.
- Appropriate respite care facilities, catering for family and individual needs. Ensuring, for example, that the cared-for person who may have dementia is not disoriented by unfamiliar surroundings, thus causing distress and adding increased worry on their carer.
- Quality of care: awareness of religious and dietary needs. Having the choice of appropriate places to provide care.
- No assumptions based on inappropriate attitudes. For example, that Black people prefer to look after their own.
- Easier access to local people. Information and provision of services in places where people meet and feel comfortable.
- A breaking-down of Black carers' fear, mistrust and suspicion of approaching services.
- A move away from the Eurocentric base of providing services which do not take account of Black people's needs.
- Black service providers running an education programme for mainstream service planners about Black carers' needs.

Black-only services may offer the ideal but there is the issue of 'who holds the purse strings'. The current power and financial base does not enable voluntary organisations to provide services without grants, service level agreements and the like. So, is it not better, since we all have to live together in one community, that we work towards breaking down the self-perpetuating racist assumptions, stereotypes and attitudes that exist, and work in partnership?

A conference held in Ealing in June 1994 to prioritise carers' needs showed that, trailing a poor tenth on a list of ten, was the provision of ethnically sensitive services. When the Black carers were asked about this, they pointed out that if other areas on the priority list were met – that is, services tailored to meet individual need – Black-specific services would not be required. Let us explore why and how.

- Essential training for service providers would be required to challenge issues of racism and deal with religious and cultural needs. It would mean staff at all levels would have to work with difference and change. The training would be multi-disciplinary, ensuring that all disciplines have a shared understanding about Black carers' needs.
- Consultation with local Black carers would need to take place. This could include developing a database of people with appropriate language skills who could facilitate service providers in their consultation and help them assess need accurately.
- Identifying in collaboration with Black carers where funding can best be placed to be most effectively used to improve support for them.
- Settings that reflect diversity, enabling the creation of an environment that nurtures and assists people to become independent, while mixing with others of different racial backgrounds.
- Ensuring effective ethnic monitoring procedures to identify, for instance, that services are being taken up by Black carers.
- Recruitment and selection of staff to ensure they represent the cultural diversity of the local area.

Whether services are provided separately or integrated for Black carers does not really matter. The issue is one of choice, ultimately, and Black carers should have the choice to use services that meet their needs. In order to achieve this, setting up alternative provision has been forced to happen. This alternative provision is not intended to be either exclusive or separatist. It is rather the exclusive design of existing services that does not cater for the needs of Black carers that has prompted the growth of specific services.

Does voluntary sector equal marginalisation for Black carers?

Meena Patel, Ethnic Minorities Manager, CancerLink

The voluntary sector has always represented creativity and flexibility and provided a ready-made source to fill the gaps in services offered by the statutory sector. So it has become the natural place for development work with carers and, in particular, Black carers. But in so doing, has this condemned Black carers' work to marginalisation, never to be part of the mainstream? Or is this no longer the case, and there are now opportunities being offered by community care to change this?

A focus on Black carers is a relatively new area of work that has developed and grown mostly over the past decade. The emphasis on Black communities had previously (and continues to be) focused on issues such as housing, finance and education. It is a recent feature that issues such as health and caring responsibilities are coming to the fore.

The task of those working on Black carers' issues is an uphill and often lonely one. They are working with concepts that Black communities do not really identify with. Many Black carers do not see themselves as 'carers'. This term has no relevance to them. As far as they are concerned, they are looking after someone, usually a family member.

So, workers are invariably starting from scratch. Their first task is the difficult one of identifying and finding Black carers, who are often invisible because they do not take up existing services. This will involve workers going out in the field to start awareness-raising about carers and carers' issues within the communities they are targeting. After consultation with carers, the development of appropriate and sensitive services begins. This means challenging existing methods of service delivery and developing new models.

In order to fully appreciate this work, however, one has to look at the other side of the coin of life in the voluntary sector. Black carers' workers often find themselves the sole worker within time-limited projects, with minimal funds. They are often left to be the 'expert' with little support in the way of adequate training, supervision and access to support groups. These are pitfalls that some organisations may bring about unintentionally. They may have been attracted by the allure of funding for Black issues and the opportunity to fulfil the need to be seen to be doing something, but failed to plan how the work is to be supported and integrated within the organisation. The focus of Black carers' work tends to be short-term, which raises expectations, only for Black carers to find that the service may only be available for two or

three years. They are then left with nothing because little is done to integrate their needs into mainstream services. This is yet another form of marginalisation.

Does community care legislation and the new contract culture offer some solutions and hope to Black carers? It emphasises user consultation in the planning of services and the inclusion of carers. This has the potential to lead to a more co-ordinated approach with Black carers in the locality, having their needs taken on board when contracts are drawn up. The voluntary sector will play a vital role, being well placed to advocate on Black carers' behalf and to provide such services. Whether community care is the solution to ensuring that Black carers are not marginalised, only time will tell. What is clear is that the responsibility for this lies with mainstream purchasers and providers.

Chapter 6

What does the future hold?

The Government's care in the community legislation intended to create *choice* and *needs-led services* for local people. These principles were at the heart of Government policy, offering elderly, disabled and mentally ill people the opportunity to be cared for in their own communities and not in large care institutions. The Government has given assurances that equality is an integral part of the reforms. The Department of Health has commissioned practice guidelines on how authorities can improve support for Black populations.

What these developments have meant for Black carers is less clear as many of them do not know the first thing about community care. Black carers claim, at meetings with their representatives, that little by way of service provision has actually changed for them since the community care reforms. They continue to be at the margins of service delivery, as we have already seen. However, local authorities, health authorities and the major carers voluntary organisations are increasingly aware of the significance of the race dimension in formulating policy. This is probably what prompted Virginia Bottomley in 1993 to remark, 'Black people have become part of the policy debate on community care.'

Community care is not a new concept to Black communities. Historically, this has meant care provided by the community for vulnerable people, supporting each other and building networks with each other. In fact, the Black voluntary sector in Britain rose out of a response to the lack of community service provision by statutory authorities. They still depend on the concept of self-help and community development. However, family patterns are changing by divorce, remarriage and, in particular, by immigration policies which have in many cases forced families to remain separated for long periods. Black people are finding it increasingly difficult to provide care within families. Even when they wish to, factors such as housing policies and economic difficulties militate against it.

Despite having more rhetoric than services in place to improve Black carers' support, many authorities have accepted the importance of supporting Black carers, and there is a genuine desire to bring about change. The community care reforms offer opportunities to ensure a more equitable distribution of services to Black people.

KEY MESSAGES

Support for Black carers could and should become a mainstream issue, through the community care planning process; through commissioning services with specifications relating to Black carers' needs; and through a monitoring process which makes equality issues a key element of 'quality'.

All health and social care agencies have a responsibility to improve support for Black carers – it is not simply the domain of Black agencies. Joint working through planning services and assessments should be more commonplace than it currently is.

The needs of local Black populations must be identified to contribute towards future planning of services. Having up-to-date information of where local Black communities live and regularly evaluating services available to them will assist with service development plans.

Cease viewing support for Black carers in terms of temporary projects using short-term money. We must consider support for Black carers as a permanent and integral part of mainstream agencies.

Support for Black carers' needs must be raised on senior management policy agendas. Where senior managers are both aware and supportive of Black carers' development work, commitment and resources to improving support is easier to achieve. For Black carers, it is an opportunity to obtain a 'slice of the cake' and for senior managers it is an opportunity to keep in touch with the realities of local carers' lives.

There is much evidence to show that poor take-up of service provision by Black carers is due to the difficulties of getting to services and the way services are publicised, organised and prioritised. As there will be more people needing care in the community, as the elderly population grows and better medical care ensures the survival of more people, Black carers will continue to have their share of being overtired and overstressed.

New challenges

The new challenge for Black carers' development work is to provide services to refugee communities who are not usually included in debates on Black carers. Their needs and voice have to be heard too, and the challenge is to find mechanisms to reach these dispersed communities whose experiences of escaping oppressive regimes do not make them readily trust authorities.

The agenda for action to support Black carers cannot rely merely on understanding their needs and offering *ad-hoc*, short-term support through projects. The language of consumerism and individual choice applies equally to Black carers too. Carers and the people they care for should have an increasing say in the services they want delivered, with a range of options offered so that service provision is tailor-made to suit individual need. This is at the heart of community care. Black carers can gain from the reforms too but not 'within the present ethnocentric and racist context of service delivery', as suggested by Atkin and Rollings.[19] Radical change is required. Specific responses in meeting Black carers' needs have to be respected or else support for them will continue to thrive at the sidelines of community care, with little impact on improving lives. At the end of the day, it will be real changes in services that we will use to judge whether Black carers and those they care for have gained anything from the reforms.

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Appendix 1

List of contacts working on Black carers' issues

Age Concern, Wandsworth (Asian Carers Project)
1c Yukon Road
London SW12

Alzheimer's Concern, Ealing
Bedford Hall
Bedford Road
London W13 0SP

Annie Wood Resource Centre
129 Alma way
Lozells
Birmingham B19 2LS

Camden Crossroads
St Margarets
25 Leighton Road
London NW5 2QD

Gloucester Black Carers Forum
c/o Community House
15 College Green
Gloucester GL1 2LZ

Hammersmith and Fulham Caring for Carers Association
Palingswick House
241 King Street
London W6 9LP

London Chinese Health Resource Centre
Queens House
1 Leicester Place
London WC2H 7BP

Medway and Gillingham Race Equality Council
16 New Road Avenue
Chatham
Kent ME4 6BA

Mencap, Leicester
35 St Nicholas Place
Leicester CE1 4LD

Oxfordshire Carers Forum
Halliday Centre
Peers Campus
Sandy Lane West
Littlemore
Oxford OX4 5JY

Pagoda Chinese Community Centre
Henry Street
Liverpool L1 5BU

Redbridge New Commonwealth Carers Group
c/o Room 227, 2nd Floor
Ley Street House
497-499 Ley Street
Ilford IG1 7QX

Sahara Asian Carers Project
Clockhouse Community Centre
Woolwich Dockyard Estate
Defiance Walk
London SE18

Time Out Respite Project
28 Beaconsfield Street
Nottingham NG7 6FD

Bengali Carers Development Worker
Carers Tower Hamlets
40 Southern Grove
London E3 4PX

Wellingborough Carers Advocacy Project
Rock Street Complex
Rock Street
Wellingborough
Northants NN8 4LW

Carers National Association, London Region, have produced a directory with details of projects set up to support Black carers in the London area.

Appendix 2

Regional forums

Both the London Black Carers Forum and the Midlands Black Carers Forum have been established since June 1994 to develop a high profile for Black carers' issues. They do this by bringing together workers from the local region to share information and ideas about developing support for Black carers. Colleagues meet regularly to learn from each other about projects set up to support carers and brainstorm new ideas for development work.

The London Black Carers Forum meets quarterly in central London. Contact details and dates can be obtained from Carers National Association, London Region office on 0171 383 3460.

The Midlands Black Carers Forum currently meets bi-monthly in Birmingham, and either Cleo Ford or Cheryl Carvey can be contacted for further details on 0121–554 7137.

BLACK CARERS in Britain face difficulties in gaining equal access to support services either because they are unaware of the services available or because they do not meet their particular needs.

Drawing on the work of the King's Fund Development Centre, this book provides information on the development of support for Black carers around the country and examines the factors which can inhibit this process, including racism, lack of joint working between statutory and voluntary organisations, and not taking the issue of Black carers seriously. It also acknowledges the many Black carers' initiatives existing in different parts of Britain and considers lessons learned which will help others interested in developing services for Black carers.

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